

**Informing the development of a self-management care
programme for older people with type 2 diabetes attending
community health centres in Cape Town, South Africa**



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May his soul rest in peace.



28 January 1967 – 27 July 2018

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Contents

Acknowledgements.....	ii
Publications and statement of contributorship.....	v
Abstract.....	xi
Chapter 1	1
Introduction	1
1.1 Study background	1
1.2. Problem statement.....	3
1.3. Purpose of the study	3
1.4. Theoretical framework.....	3
1.5. Study objectives	3
1.6. Outline of thesis	4
1.8. Chapter summary	5
Chapter 2	10
Literature review	10
2.1. Chapter outline.....	10
2.2. Part 1: Population ageing in Africa	10
2.2.1. Demographic profiles of older persons in South Africa	11
2.2.2 The social and economic situation of older people in South Africa.....	13
2.2.2. Health profile of older persons in South Africa	14
2.3. Part 2: Diabetes mellitus in older persons	15
2.3.1. Definition and classification of diabetes	15
2.3.2. Epidemiology of type 2 diabetes mellitus and an ageing population.....	16
2.3.3. Diagnosis and diagnostic criteria of diabetes in older persons	17
2.3.4. Diabetes complications and multimorbidity in older persons	18
2.4. Part 3: Diabetes care in sub-Saharan Africa	18
2.4.1. Challenges of diabetes care in South Africa.....	19
2.5.1. Self-management care and support in older persons.....	23
2.5.2. Diabetes self-management education for older persons.....	23
2.5.3 Self-management care challenges in older persons.....	24
2.5. Part 4: Theories and models for health promotion.....	26
2.5.1 Theories and models.....	27
2.5.2. Individual level theories	28
2.5.3. Interpersonal level theories	29

2.5.4. Programme and strategy planning models — multiple levels.....	29
2.6. Chapter summary	32
Chapter 3	41
Research design and methods.....	41
3.1. Chapter outline.....	41
3.2. Research Design.....	41
3.2.1. Applying the PRECEDE component of the PRECEDE-PROCEED model.....	41
3.3. Justification of mixed method design choice in this thesis	43
3.4. Justifications for using systematic reviews.....	43
3.3. Methodology of different phases/studies of the research study.....	43
3.3.1.Phase 1: Social assessment	43
3.3.2. Phase 2: Epidemiological assessment.....	45
3.3.3. Phase 3: Educational and ecological assessment	45
3.3.4. Phase 4: Administrative and policy assessment and intervention alignment...	46
3.6. Data collection and analysis of the research study	47
3.7. Ethics approval	47
Chapter 4	50
Study 1: The prevalence of type 2 diabetes among older people in Africa: a systematic review and meta-analysis.....	50
4.1 Abstract	51
4.2. Introduction	52
4.3. Methods	52
4.3.1. Literature search.....	52
4.3.2. Assessment of risk bias in included studies	55
4.3.3. Data extraction	55
4.3.4. Data synthesis and analysis	55
4.4. Findings	56
4.4.1. Search results	56
4.4.2. Prevalence by age, sex, region, and type of residency.	57
4.4.3. Prevalence by method of data collection (STEPS vs non-STEPS).	65
4.4.4. Prevalence by diagnostic method (FPG vs OGTT).....	67
4.4.5. Investigation of the sources of heterogeneity	69
4.5. Discussion	69
4.6. Conclusion	74
Chapter 5	81

Study 2: Diabetes in South African older adults: prevalence and impact on quality of life and functional disability – as assessed using SAGE Wave 1 data.	81
5.1. Abstract	82
5.2. Background	83
5.3. Methods	84
5.3.1. Data source	84
5.3.2. Measurements.....	85
5.3.3. Ethical clearance	86
5.4. Statistical analyses	86
5.5. Results	87
5.6. Discussion	93
5.7. Conclusion	96
Chapter 6	101
Study 3: Does social support effect knowledge and diabetes self-management practices in older persons with Type 2 diabetes attending primary care clinics in Cape Town, South Africa?	101
6.1. Abstract	102
6.2. Introduction	103
6.3. Methods	104
6.3.1. Study design and selection of participants	104
6.3.2. Instruments	105
6.3.3. Data collection	105
6.4. Data analysis	105
6.5. Results:	106
6.5.1. Descriptive and bivariate analysis.	106
6.6. Discussion	115
6.7. Conclusions	117
Chapter 7	124
Study 4: current policies and practice for the provision of diabetes care and self-management support programmes for older South Africans.....	124
7-1 Abstract	125
7.2 Background	126
7.3. Methods	127
7.4. Data analysis	128
7.5. Findings	128
7.7. Conclusion	142

Chapter 8	146
Study 5: The effectiveness of peer and community health worker-led self-management support programs for improving diabetes health-related outcomes in adults in low-and-middle-income countries:	146
A systematic review.....	146
8.1. Abstract	147
8. 2. Introduction	148
8.3. METHODS	150
8.3.1. Search strategy.....	150
8.3.2. Selection of studies.....	151
8.3.3. Assessment of risk of bias of studies	152
8.3.4. Data extraction and synthesis	152
8.4. Taxonomy for analysing implementation strategies:.....	153
8.4.1. Taxonomy for evaluating the implementation strategies:	153
8.5. Statistical analysis.....	154
8.6. Results	154
8.6.1. Summary of the searches	154
8.6.2. Quality of included studies	155
8.6.3. Taxonomy of Implementation of peer support strategies.....	157
8.7.5. Implementation fidelity of all the included studies.....	169
8.7. Discussion	174
8.8. Conclusion	175
Chapter 9	181
SUMMARY AND CONCLUSIONS	181
IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH	181
9.1. Chapter outline.....	181
9.2. Principal findings	181
9.3. Implications for policy and practice.....	185
9. 4. Implications for future research	186
9.5. Strengths and limitations of this research study	187
10. APPENDICES.....	189
10.1. Appendix 1: the prevalence of type 2 diabetes mellitus among older people in Africa: a systematic review protocol.	190
10.2. Appendix 2: Effectiveness of community-based peer led diabetes self-management programmes (COMP-DSMP) for improving clinical outcomes and quality of life of adults	

with diabetes in primary care settings in Low and middle-income countries (LMICS): a systematic review protocol.....	1891
10.3. Appendix 3: Ethics approval.....	1892
10 .4. Appendix 4: Study 1: Supplementary Materials.....	1893
10 .5. Appendix 5: Study 2: Supplementary Materials.....	212
10 .6 Appendix 6: Study 3: Supplementary Materials.....	226
10 .7 Appendix 7: Study 4: Supplementary Materials.....	253
10 .8 Appendix 8: Study 5: Supplementary Materials.....	258

Informing the development of a self-management care programme for older persons with type 2 diabetes in Community Health Centers in Cape Town, South Africa

Abstract

Diabetes is a growing problem globally, with the major impact being experienced in low and middle-income countries. In 2017, there were an estimated 122.8 million people over the age of 65 years living with diabetes globally, with a prevalence of 18.8% and 3.2 million deaths at this age. If the trends continue, the number of people living with diabetes over the age of 65 years will be 253.4 million in 2045. This is being driven by demographic changes including the ageing of the population. In South Africa, diabetes is a major cause of morbidity and mortality and a burden to the overstretched health services, community, family and people with the disease. Self-care management is a cornerstone of diabetes care. The purpose of this thesis is to inform the development of a self-care management programme for older people attending public sector primary health care services in Cape Town, South Africa by using the PRECEDE planning model. This model provides an eight-phase framework for health care professionals to determine, develop, implement and assess health promotion programmes, as well as the application of health promotion theories systematically within such programmes.

The thesis incorporates five interlinked studies, presented as five publications, two published and three in review: The first was a systematic review of studies that assessed the prevalence of type 2 diabetes mellitus among older people in African countries conducted between 2000 and 2015 with the objective of providing data for the monitoring of future trends. This demonstrates that type 2 diabetes is not rare in individuals aged 55 years and older across Africa – the overall prevalence of diabetes was 13.7% (95% CI 11.3–16.3) and was twofold higher in studies based on the oral glucose tolerance test than in those using fasting plasma blood glucose. The second is a secondary analysis of the Study on global AGEing and adult health (SAGE) South Africa Wave 1 data that examined the prevalence of self-reported diabetes and the association between diabetes and each of health-related quality of life and disability amongst South Africa's older adults. The results were that diabetes was associated with lower quality of life and greater

disability: it represented not only a risk factor for disability but was associated with a range of impairments and co-morbidities predisposing to loss of autonomy.

The third, a cross-sectional survey, examines the knowledge of older people with diabetes attending primary care clinics in Cape Town, South Africa, about living with and managing their diabetes; and aims to determine the relationship of social support, especially that of family and friends with their self-management. Its major finding is that there was a lack of knowledge about the complications of diabetes, suggesting that the available diabetes educational opportunities have not been effective. Importantly, however, social support was positively associated with both knowledge and a number of self-care aspects. The fourth is a qualitative study consisting of documentary review and individual interviews with key informants to investigate the current policies, programmes and any other interventions as they relate to older people with diabetes. This found that generally older persons face numerous barriers in managing their condition. Further, there are multiple efforts to re-orientate the healthcare system to focus more effectively on non-communicable diseases for the population which would benefit older patients with diabetes. Finally, the study includes a systematic review of peer and non-professional health worker-led diabetes self-management programmes (COMP-DSMP) in low and middle-income country primary health care settings, and also examines the implementation strategies and associated diabetes-related health outcomes. This found equivocal evidence supporting the use of COMP-DSMP for people with diabetes in these countries and suggested that the models of a peer/CHW-led programme need to be further explored, especially given the inevitability of a professional healthcare workforce shortage in LMICs.

In conclusion, this research study has described the extent of the need for developing and evaluating education programmes that focus on older people with diabetes and emphasises the role of family and friends. Whilst there have been some significant policy interventions pertaining to the protection of the health and welfare of older persons in SA, the needs of this vulnerable group remain relatively low on the list of priorities in terms of focus and resource allocation. In this context, older people, as a distinct group, are also not a strong focus in current health policy relating to the provision of NCD care. This thesis alerts policymakers and clinicians to some of the specific issues considered to be pertinent and important in the care and management of older persons with diabetes. Many of these would also be applicable to older individuals with other chronic conditions.

List of tables

- . Table 2–1. Percentage growth in the population of older persons, 2001–2016 by Province in South Africa
- Table 2–2. Distribution of persons aged 60 years and older by age and sex, 2011 and 2016 in South Africa.
- Table 2–3 1999 WHO criteria for the diagnosis of diabetes.
- Table 2–4. Key elements of theoretical models of health promotion.
- Table 4-1: Summary and comparison statistics.
- Table 4- 2. Prevalence of type 2 diabetes in older populations assessed in studies not using the WHO STEPwise approach to surveillance.
- Table 4–3. Prevalence of type 2 diabetes in older populations assessed in studies using the WHO STEPwise approach to surveillance.
- Table 5–1. Number and percentage of participants by socio-demographic characteristics, self-reported health behaviours and co-morbidities.
- Table 5–2. Association of diabetes, sociodemographic characteristics, self-reported health behaviours and co-morbidities with WHOQOL (0-100).
- Table 5–3. Association of diabetes, sociodemographic characteristics, self-reported health behaviours and co-morbidities with WHODAS (0-36).
- Table 6–1. Socio-demographic and clinical characteristics of the study participants.
- Table 6–2. Knowledge, self-management practice, social support scores.
- Table 6–3. Self-management practice of lifestyle risk factors.
- Table 6–4. Social support assessment of the study participants.
- Table 6–5 The ordinal logistic regression models of knowledge, self-management practice with the components of social support scale.
- Table 7–1 Table 7-1 The key to the labelling of key informants
- Table 8–1. Risk of bias for included studies.
- Table 8-2. Taxonomy of implementation of peer-support strategies in LMIC by mode of delivery.
- Table 8-3: Assessment of the implementation outcomes of diabetes self-management peer support strategies in LMIC by mode of intervention delivery.
- Table 8-4. Summary of intervention effects on clinical, behavioural and psychological outcomes by study design.
- Table 8–5. Assessment of elements of implementation fidelity.

List of Figures

Figure 2–1 Population aged 60-79 years and 80 years or over in sub-Saharan Africa, 1990-2050.

Figure 2–2. The percentage of the population 60 years and over in African countries, 2000 and 2030.

Figure 2–3. Risk factors contributing to the high prevalence of T2DM in older persons.

Figure 2–4. Types of health services used by older persons aged 60 years and older, by province, in South Africa 2015.

Figure 2–5 Innovative Care for Chronic Conditions Framework (ICCC)

Figure 2–6. The Precede-Proceed Model. From Green and Kreuter 2005

Figure 3–1. The flowchart shows the different phases of PRECEDE-planning model used in the study

Figure 4–1. Selection of articles for inclusion in the systematic review.

Figure 4-2. Meta-analysis results for prevalence of type 2 diabetes in studies using the WHO STEPwise approach to surveillance.

Figure 4-3. Meta-analysis results for prevalence of type 2 diabetes in studies not using the WHO STEPwise approach to surveillance.

Figure 4-4. Meta-analysis results for prevalence of type 2 diabetes in studies in which diabetes diagnosis was based on fasting plasma glucose.

Figure 4-5. Meta-analysis results for prevalence of type 2 diabetes in studies in which diabetes diagnosis was based on using the oral glucose tolerance test.

Figure 6–1a. Distribution of correct answers to questions on Knowledge on Symptoms and Complications of Diabetes and hypertension (n = 406) .

Figure 6–1b. Distribution of correct answers to questions on diabetes self-management knowledge.

Figure 7-1: summarises all main themes (from the doc review and the KI interviews).

Figure 7–2. Barriers to effective self-management for older persons: the views of key informants.

Figure 8–1. The PRISMA flow diagram depicting the flow of information through the different phases of the systematic review.

Figure 9–1. The application of PRECEDE planning model for the development of self-management care for older people in Cape Town City, South Africa.

List of Abbreviations and Acronyms

Acronyms	Name in full
AADE	The American Association of Diabetes Educators
ADA	The American Diabetes Association
AGS	American Geriatric Society
DSME	Diabetes Self-Management Education
DESMOND	Diabetes Education and Self-Management in Ongoing and Newly Diagnosed
DCP	Diabetes Care Profile
DSMP	Diabetes self-management practice
DM	Diabetes mellitus
EDWPOP	European Diabetes Working Party for Older People
FPG	Fasting plasma glucose
GDM	Gestational diabetes mellitus
HbA1c	Glycated haemoglobin
HICs	High-income countries
IDF	International Diabetes Federation
IGT	Impaired glucose tolerance
IFG	impaired fasting glucose
LE	Life expectancy
LMICs	Low-income countries
MM	Mixed methods
NDOH	National Department of Health
OGTT	Oral glucose tolerance test
PHC	Primary healthcare
PPM	PRECEDE-PROCEED model
RR	Relative risk
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses.
SAGE	Study on Global AGEing and Adult Health (SAGE),
SA	South Africa
SEMDSA	Society for Endocrinology, Metabolism and Diabetes of South Africa

SSA	Sub-Saharan Africa
T1DM	Type 1 Diabetes mellitus
T2DM	Type 2 Diabetes mellitus
UNDESA	United Nations Department of Economic and Social Affairs
WHO	World Health Organisation
WHOQoL	WHO Quality of Life
WHODAS	WHO Disability Assessment Schedule

Chapter 1

Introduction

1.1 Study background

Population ageing is a global phenomenon. However, the definition of old age varies across countries and regions, influenced to an extent by demographic trends, such as high or low life expectancy, and social, cultural and political factors (1). The World Health Organization (WHO) posits the chronological age of 65 years as an acceptable definition of older persons in developed countries. This like many westernized concepts, may not be appropriate or directly translatable to all of Africa, but as a result of the changing in legislation via the Social Assistance Amendment Act, 6 of 2008, South Africa aligned itself with the WHO's definition of the 'older persons' as all persons over the age of 65 years (2-3).

At present, there are approximately 600 million people over the age of 60 globally. This number is projected to increase to approximately 2 billion by 2050 (1). There were in Africa an estimated 50.5 million people of the same age group in 2007 and 64.5 million in 2015; this number is projected to exceed 103 million in 2030 and 205 million in 2050; with the annual growth rate exceeding that of the general population (2). South Africa (SA) is also experiencing the ageing of its population, driven by declining fertility and mortality. There the population aged 60 years and older numbered over 4.5 million in 2016, thereby accounting for just over 8% of the South African population (3-4).

The number of people with diabetes globally is also increasing. According to the updated figures of the International Diabetes Federation (IDF) Atlas 8th edition, it has been projected that there would be a rise from 451 million people with diabetes in 2017 to 693 million by 2045 (5). In 2017, there were an estimated 122.8 million people over the age of 65 years living with diabetes, with a prevalence of 18.8% and 3.2 million deaths at this age which counts for more than 60% of all deaths attributable to diabetes in people over the age of 17 years. If the trends continue, the number of people living with diabetes over the age of 65 years will be 253.4 million in 2045 (5).

The 8th edition of the IDF Atlas (2017) estimated 15.9 million people aged 20–79 have diabetes in the sub-Saharan Africa (SSA) region, representing a prevalence of 2.1–6.7%. SSA has the highest percentage of undiagnosed cases of diabetes; over two-thirds (66.7%) of individuals with diabetes are unaware of their status (6). The majority of individuals with diabetes (58.8%) live in towns, although the population in the region (61.3%) is mainly rural. It is concerning that studies suggest that Africa has the highest age-specific mortality rate in the world (6–7).

In South Africa, non-communicable diseases (NCDs), including diabetes, continue their increase in the rankings of top 10 leading causes of death, with DM moving from the third position in 2014 to the second position in 2015 (8). NCDs accounted for 63% of the top 10 leading causes of death among women aged 65 and above, whereas among men in the same age group these constituted 48.0% (8). The rising number of people with DM together with other NCDs added to the other ongoing burdens of HIV/AIDS, and Tuberculosis (TB) is causing a major impact on the country's healthcare system, in particular, the primary healthcare facilities (9) – originally equipped to deal with patients with acute conditions – are now struggling to provide adequate care for those with NCDs. Therefore, levels of control of diabetes are poor, leading to high rates of complications (9–11).

Older persons with diabetes are at a higher risk of microvascular and macrovascular disease such as ischaemic heart disease, peripheral artery disease, stroke, heart failure, and chronic kidney disease (12–15). Additionally, their demands for hospital care are increased two to three times compared with an aged-matched non-diabetes population,(18) with more frequent clinic visits and a five-fold higher admission rate. Acute hospital admissions account for 60% of total expenditure in this group (18).

Given that patients visit healthcare professionals only periodically, health promotion activities focused on self-management is vital to the maintenance of long-term health for older persons. (19) Self-management is a process whereby persons and their families maintain health through health-promoting practices and managing disease. Individuals use self-management as they respond to signs and symptoms when they occur (20). Self-management in diabetes focuses on a balance of dietary intake, exercise, medication management and the self-monitoring of blood glucose (SMBG) which constitutes its four main cornerstones (21). Individuals who engage in self-care maintenance adhere to those behaviours needed to maintain physical and emotional stability.

Self-management is an essential element of the Chronic Care Model (CCM), it develops the role of healthcare professionals from delivering information and traditional patient education to include helping patients build confidence and make choices that lead to improved self-management and better outcomes (22–26). The literature on diabetes encompasses evidence that specific self-management interventions, including the introduction of blood glucose-lowering medications or new insulin delivery systems, and educational and counselling interventions designed to facilitate the development of diabetes-specific coping skills, can improve both glycaemic control and quality of life in people with diabetes (27–34). Thus, to preserve the best possible quality of life, the person diagnosed with diabetes must be supported in overcoming any barriers associated with older age and his or her diabetes care. It has been recommended that age does not influence a person's ability to learn new diabetes management skills (35–40). However, self-management is challenging for all those with the condition but is likely to create a higher demand for those who may have

existing co-morbidities associated with age and long-standing chronic illnesses such as diabetes. (37).

1.2. Problem statement

Because of concerns about cognitive problems and co-morbidities, individuals older than 65 years are often excluded from clinical research trials. As a result, there is little evidence globally, let alone in LMICs, on how best to support older persons' self-management efforts (37). Although there are numerous guidelines for the management of diabetes, only a few are specifically designed for older persons with diabetes (38-40). Furthermore, the current support programmes, particularly those that are disease-specific, such as those for diabetes, may not be relevant to the specific self-management support needs of older persons with multiple co-morbidities or chronic disability (41–43). Additionally, many frail older individuals do not only suffer from multiple diseases: cognitive impairments and poor mental health often also coexist (44). Hence, research is needed to find out which approach in management best meets the needs of the older people with diabetes (45). In South Africa, little is known about older people's knowledge about living with and managing their diabetes and the complications and challenges they face as regards an adherence to lifestyle changes. Self-management approaches are needed to limit the consequences of this chronic illness for older persons and society(46-48). This is recognised as a gap in the research literature.

1.3. Purpose of the study

This study sets out to fill the current gaps in knowledge of diabetes in the older person in South Africa, with a view of developing a diabetes self-care management programme targeted at this group and therefore limiting the impact of the disease and improving their health-related quality of life. Furthermore, the study findings may provide the healthcare professional and health policymaker with a better understanding of self-management practice of older persons with diabetes attending primary care settings in Cape Town, South Africa where little research has been done.

1.4. Theoretical framework

The critical question of health promotion programme planning is to understand what the community wants, what is needed, and, what can be done. The three areas overlapped represent what can be achieved, but, resources, time and other boundaries do not allow everything to be addressed and so areas must be prioritised (49). This study is framed within the PRECEDE-PROCEED theoretical model (50–51) and uses a mixed-methods approach with the following objectives:

1.5. Study objectives

Objective 1: To examine the association between self-report diabetes and each of health-related quality of life and disability amongst South Africa's older adults.

Objective 2: To conduct a systematic review of studies assessing the prevalence of type 2 diabetes mellitus among older people in African countries.

Objective 3: To investigate the status of knowledge, self-management practice, and social support for South African older persons with type 2 diabetes and determine the relationship of social support, especially that of family and friends with their self-management.

Objective 4: To identify and explore emerging policies and practices in diabetes self-management care for older persons in South Africa.

Objective 5: To conduct a systematic review assess peer and non-professional health worker-led diabetes self-management programmes in the low and middle-income country (LMIC) primary healthcare settings, examine the implementation strategies, and associated diabetes-related health outcomes.

1.6. Outline of thesis

The thesis is structured as follows. Chapter 2 provides a comprehensive literature review of the major concepts in the study. Chapter 3 briefly describes the methodological approaches that were undertaken for each of the objectives by applying the PRECEDE planning phase (Phase 1 to Phase 4). The 5 papers relating to the various objectives are to be found in Chapters 4 to 8. The paper in Chapter 4 presents the systematic review of studies assessing the prevalence of type 2 diabetes mellitus among older people in African countries conducted between 2000 and 2015 with the objective of providing data for the monitoring of future trends. The paper in Chapter 5 examines the prevalence of self-report diabetes and the association between diabetes and each of health-related quality of life and disability factors amongst South Africa's older adults as assessed using SAGE Wave 1 data. The paper in Chapter 6 examines the knowledge of older people with diabetes attending primary care clinics in Cape Town, South Africa about living with and managing their diabetes; and to determine the relationship of social support, especially that of family and friends with their self-management. The paper in Chapter 7 reviewed current policies, programmes and any other interventions as they relate to older people with diabetes. The paper in Chapter 8 presents the systematic review to assess peer and non-professional health worker-led diabetes self-management programmes in the low and middle-income country (LMIC) primary healthcare settings, examines the implementation strategies, and associated diabetes-related health outcomes. Chapter 9 provides a summary of the major findings in the context of public health, practice, policy impact, recommendations regarding the self-management care programme development and other appropriate strategies and future research.

1.8. Chapter summary

In this chapter an overview of the study context, aims, objectives and theoretical framework has been presented and the research work done for this PhD thesis briefly described, so as to inform the development of a self-care management programme for older persons with type 2 diabetes who live in Cape Town, South Africa.

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Chapter 2

Literature review

2.1. Chapter outline

This literature review provides an overview of literature dealing with population ageing in Africa and South Africa; diabetes mellitus in the ageing population; the challenges of managing diabetes in African settings; diabetes self-care management/education; the challenges faced by older people in primary healthcare settings; and concludes with a description of the health promotion theoretical framework that underpins the body of this work. Library database searches were undertaken in medical and healthcare fields for relevant papers and reports in the last fifteen years (2000–2015) since significant developments in diabetes management have been published in that time.

2.2. Part 1: Population ageing in Africa

According to the United Nations Department of Economic and Social Affairs (UNDESA) 2017 Revision, the world's population numbered nearly 7.6 billion as of mid-2017(1). Africa is often referred to as the youngest continent regarding age structure (2). However, this is changing dramatically, and the continent is projected to experience the fastest rate of growth of numbers of older persons than any other continent by 2050 (3). The number of persons aged 60 and over in Africa is expected to increase from 50.5 million in 2007, to 64.5 million in 2015, and to reach 205 million by 2050 (3). This represents a rate of increase of double the yearly population growth, with the figure of older individuals in the population increasing at an annual rate of 3.1% between 2001 and 2015 and of 3.3% between 2015 and 2050, as shown in Figure 2.1 (3).

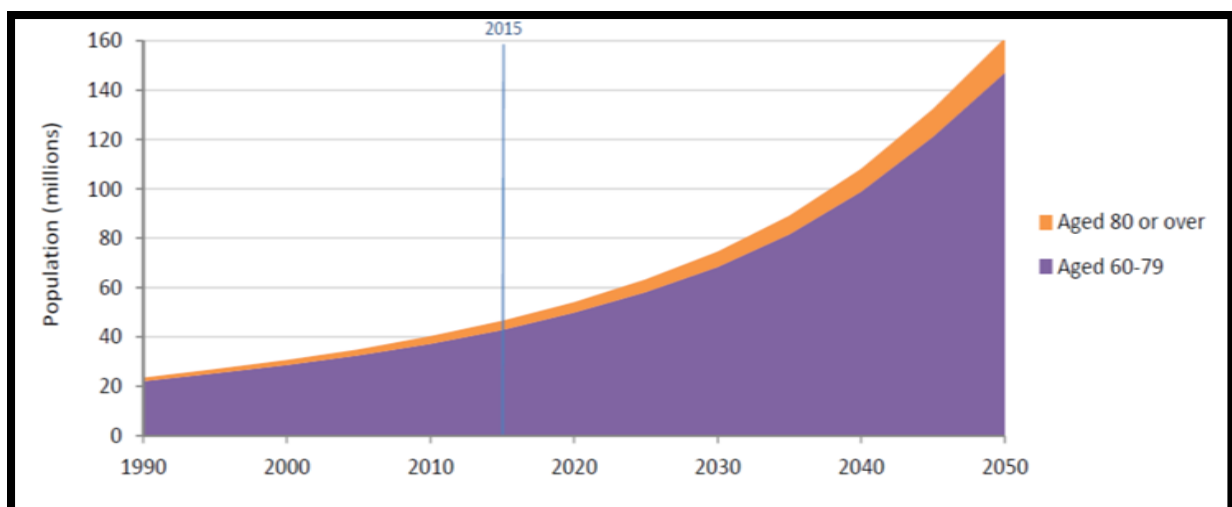


Figure 2–1 Population aged 60–79 years and 80 years or over in sub-Saharan Africa, 1990–2050 (3)

As seen in Figure 2–2, in 2000 South Africa, had the greatest proportion of older people in its population (7%), in Africa, followed by Cameroon with 5.2% and Ghana with 5.1% (4). The World Health Organisation (WHO) estimates suggest that the ageing population of South Africa will increase to 11.5% in 2030, followed by Ghana with 9.5% and Kenya with 6.7% (Figure 2–.2) (4). The latest WHO predictions are that South Africa's older population is projected to more than double, from 7.2% to 15% of the country's total population by 2050 (5) and from about 4.2 million to 10.6 million.

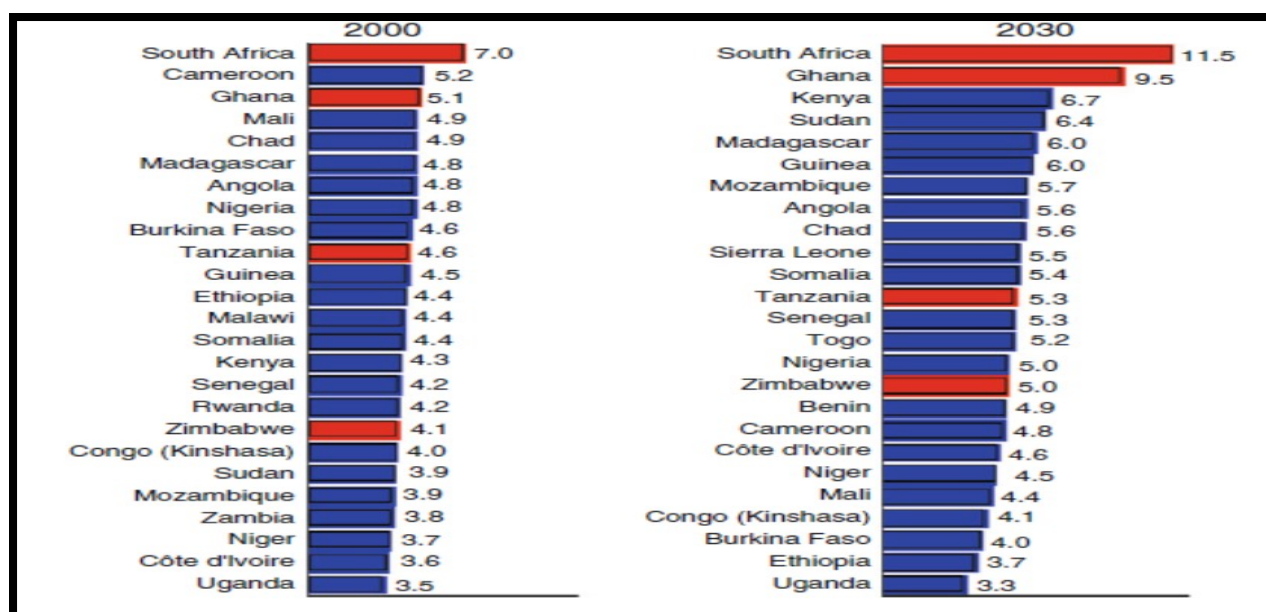


Figure 2–2 The percentage of the population 60 years and over in African countries, 2000 and 2030 (4).

2.2.1. Demographic profiles of older persons in South Africa

There have been a few reports about the rise in the ageing population in SA over the past few years. The percentage population growth of older persons by province in South Africa is shown in Table 2–1. (6) The provincial variations show that the population size of older persons was 6.2% to 9.2% in 2001 and 6.8% to 9.5% in 2016. (6) In 2016, the highest population growth of older people was documented in the Northern Cape, where the older persons represented almost 10 % of the provincial population, followed by the Western Cape with a 9.5% growth rate. These variations can be attributed mainly to the outmigration of young people in search of opportunities, in the case of the Northern Cape, and because of an inflow of the older persons, in the case of Western Cape, as the province is generally observed as a good retirement destination.(6)

Table 2–1 Percentage growth in the population of older persons, 2001–2016 by Province in South Africa (6)

Province	2001	2007	2011	2016
Western Cape	7.8	8.6	8.9	9.5
Eastern Cape	9.2	9.6	9.7	8.1
Northern Cape	8.2	9.0	8.6	9.6
Free State	7.3	8.0	8.3	8.7
KwaZulu-Natal	6.9	7.0	7.6	7.3
North West	7.3	7.6	8.3	8.0
Gauteng	6.2	6.9	6.9	8.7
Mpumalanga	6.3	6.5	7.0	6.8
Limpopo	7.7	8.5	8.6	7.6
South Africa (Overall)	7.3	7.8	8.0	8.1

Table 2–.2 shows the population distribution of older persons by age and sex. Between 2011 and 2016, the age group 60–64 contained the largest proportion of older persons, followed by age group 65–69, whilst the age group 85+ comprised only 5% of older people in 2016. (8) There was a higher proportion of men than women amongst the age groups 60–64 and 65–69, but this changed after the age of 70 years. (6) This demonstrates the ageing phenomenon in which women tend to live longer than men and hence constitute the majority of the older people. In 2016, there was an increase in the proportions of older persons among both sexes in the age groups 60–64, 65–69 and 70–74. After age 75, there is a steady decline in the percentage of older persons for both sexes, with a sharper decline for men than for women. (6)

Table 2–2 Distribution of persons aged 60 years and older by age and sex, 2011 and 2016 in South Africa (6).

Age group	Male		Female		Both sexes	
	N ('000)	Per cent	N ('000)	Per cent	N ('000)	Per cent
2011						
60–64	612	37,1	773	30,9	1386	33,4
65–69	402	24,4	556	22,2	958	23,1
70–74	293	17,8	455	18,2	748	18,0
75–79	165	10,0	316	12,6	481	11,6
80–84	101	6,1	222	8,9	323	7,8
85+	76	4,6	180	7,2	256	6,2
Total	1 649	100,0	2 503	100,0	4 152	100,0
2016						
60–64	704	38,8	869	32,1	1573	34,8
65–69	500	27,6	679	25,1	1179	26,1
70–74	320	17,6	505	18,6	825	18,2
75–79	163	9,0	323	11,9	486	10,7
80–84	74	4,1	177	6,5	251	5,5
85+	53	2,9	158	5,8	211	4,7
Total	1 815	100,0	2 710	100,0	4 525	100,0

Source: Report: Vulnerable Group Series II 2011–2016 (6)

2.2.2 The social and economic situation of older people in South Africa

The social and economic situation of older persons in SA is deteriorating, migration and urbanisation poor education, unemployment, lack of access to basic services and poverty and the huge burden of HIV and NCDs had been identified as contributing factors to the destabilisation the older persons in a closely-knit age-integrated African society (6). These factors have combined to impact not only older people's financial security but also traditional levels of respect and valuing (6).

2.2.2.1. Living arrangements:

The living arrangements of older persons are made up of many factors, including cultural values regarding co-residence and intergenerational ties and family support. Between 2011 and 2015, the proportions of older persons living alone increased by 1.4 percentage points from 8.8% to 10.2%. (7). In South Africa and elsewhere, living alone poses certain risks for older people, especially if they have limited resources to sustain themselves. Living arrangements are reported to influence an older person's ability to access services, including healthcare and social support to ensure their needs are met as they age. (7)

2.2.1.2. Old-age grant

Over time, South Africa has experienced a decline in the proportion of economically active people employed by the formal sector, because of the shrinking of the national economy. This has led to the retrenchment of workers and/or compulsory early retirement, although there has been expansion of the informal sector (7). Concerningly, the high levels of unemployment and poverty in

the country is making it difficult to save for old-age. This means that a growing proportion of the population is likely to be poor and in need of state support for their health and welfare needs (7).

An old-age grant is a monthly income that is managed by the South African Social Security Agency (SASSA), a government agency. (8) In SA, over 3.1 million of persons aged 60 years and older received an old-age grant in 2015 compared to 2.6 million in 2011. The grant is paid out only to people whose financial income is below a certain level. It is the main source of income for most of the older persons in South Africa but, in many cases, older persons use their grants to support the entire family, which is mostly multigenerational. (8) In addition, people receiving old-age grants are open to financial abuse by other family members and may not fully benefit from this income. (8)

Vulnerability to poverty is compounded by cumulative inequalities over the life course and health, function and survival are unequally distributed across the population. Poverty and poor living conditions significantly exacerbate the degenerative effects of ageing, increasing the likelihood of ill-health, disability and cognitive decline. (8)

For those older people whose physical health enables them to pursue income generation activities there is often the obstacle of lack of opportunity. It is in the interest of the SA government to consider what potential exists to create employment opportunities or to support sustainable livelihoods for older persons (7).

2.2.1.3. Educational attainment

Low levels of educational attainment in South Africa often translate into poor living circumstances, as they have a bearing on the type of employment and income levels during a person's economically productive years as well as their ability to be financially independent after retirement. (9) Poor literacy levels are an essential factor that contribute to the negative well-being of older persons and their involvement in society. Literacy prevents social exclusion, especially when social interaction is made possible via various languages. (9)

2.2.2. Health profile of older persons in South Africa

As mentioned earlier, older persons are generally documented as a vulnerable group in need of special care and attention. The HIV/AIDS epidemic with resultant high mortality rates led to a 'hollowing out of a generation' – a middle generation that traditionally took care of older people, now leaving these older people – grandparents – to take care of AIDS orphans.(10) The impact is demonstrated by a qualitative study in Western Cape townships, that found that grandmothers caring for a child with HIV/AIDS reported poorer socio-economic circumstances and health because of the economic and physical demands of caregiving (10-11).

The increase in numbers of older persons in societies presents challenges which will result in greater problems in healthcare systems. (12) However, the challenge is predominantly significant in Africa, heightened by the concurrent problems of the highest global levels of poverty and the HIV/AIDS pandemic which affect the quality of life of millions of people and impact mainly older individuals who will need to combat a variety of co-morbidities. (13–14) In South Africa, the prevalence of NCD-related disability tends to increase with age, which increases the demand on health systems for the prevention and treatment of NCDs, including diabetes and their associated complications (15–16). In 2015 the three health conditions most common among the older South Africans were high blood pressure 45.3%, diabetes 15.8% and arthritis 13.8%. (17).

2.3. Part 2: Diabetes mellitus in older persons

In this section, the definition, classification, epidemiology, diagnosis, complications and co-morbidity of diabetes mellitus is discussed briefly.

2.3.1. Definition and classification of diabetes

Diabetes mellitus (DM) defines a group of metabolic disorders characterised by increased blood glucose concentration. (18) Individuals living with diabetes have a higher risk of developing some life-threatening severe health problems resulting in higher medical care costs, a reduced quality of life and increased mortality. Persistently high blood glucose levels cause generalised vascular damage that affects the heart, eyes, kidneys and nerves and results in several complications. (18) There are three main types of diabetes: type 1 diabetes, type 2 diabetes and gestational diabetes (GDM):

2.3.1.1. Type 1 diabetes mellitus

Type 1 diabetes (T1DM), previously known as insulin-dependent or juvenile-onset diabetes, is an autoimmune disease in which the body's immune system reacts against and destroys the insulin-producing beta cells in the islets of Langerhans of the pancreas. (19)

2.3.1.2. Type 2 diabetes mellitus

Type 2 diabetes mellitus (T2DM), earlier known as non-insulin dependent or mature-onset diabetes, is characterised by insulin resistance and relative insulin deficiency. (19) It has a genetic component, and lifestyle factors such as overweight, physical inactivity and inappropriate nutrition can trigger its development. (19) Internationally, it is the most prevalent form of diabetes, affecting 85–95% of all diabetics in High-Income Countries (HICs), with a higher proportion in Low-Income Countries (LMICs). T2DM occurs mainly in mature adults with the prevalence increasing in older age population. (19)

2.3.1.3. Gestational diabetes mellitus

Gestational diabetes mellitus is carbohydrate intolerance of variable severity which is first diagnosed during pregnancy. It is often mentioned as the most frequent complication of pregnancy. (20)

2.3.2. Epidemiology of type 2 diabetes mellitus and an ageing population

As seen in Figure 2–5, there are several risk factors proposed for the T2DM. Regardless of the genetic component, it is evident that many environmental and lifestyle factors can increase the possibility that a genetically susceptible individual will develop the disease in old age. (21) The results of large epidemiologic studies have demonstrated that diabetes is more likely to develop in older individuals who have a diet that is high in saturated fats and simple sugars and low in complex carbohydrates (22). Obesity with a central distribution of body fat, and a decrease in physical activity occur progressively with ageing, and both factors are associated with abnormal carbohydrate metabolism. (23)

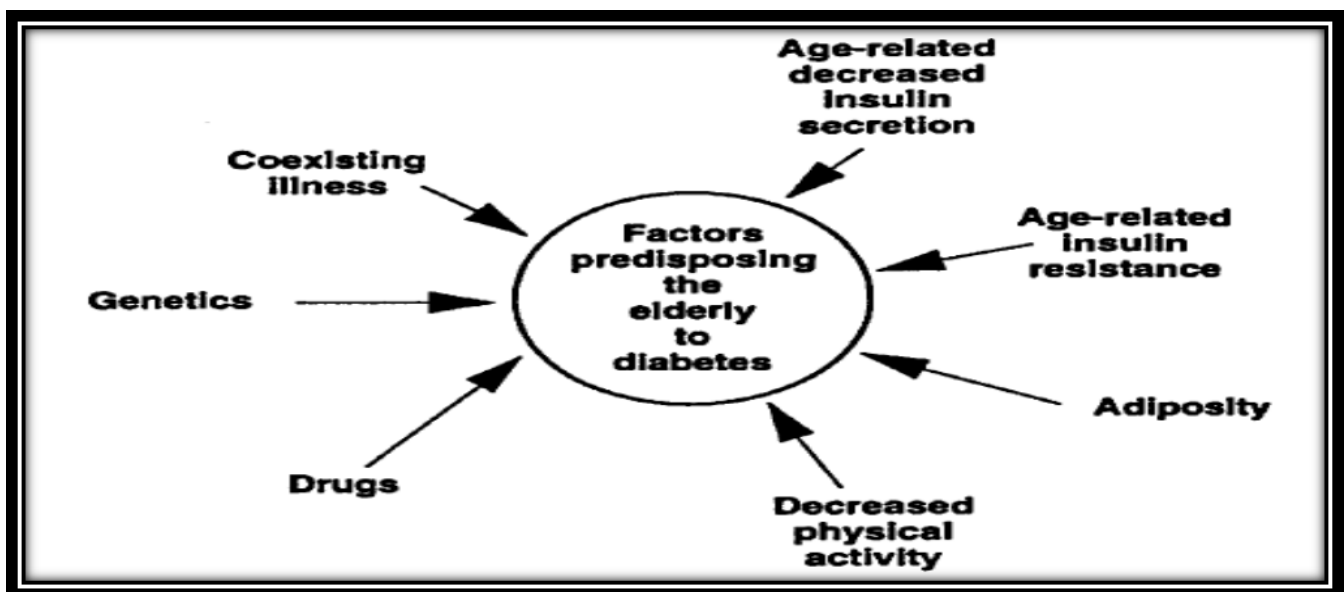


Figure 2–3 Risk factors contributing to the high prevalence of T2DM in older persons (36)

It was estimated that in 2017 there were 451 million people with diabetes globally. These numbers were projected to increase to 693 million by 2045. (23) In 2017, it was estimated that nearly half of all people (49.7%) living with DM were undiagnosed, almost 5 million deaths worldwide were attributable to diabetes in the 20–99 years age range and healthcare expenditure on people with diabetes was estimated to be USD 850 billion globally. (23)

In 2017, an estimated 14.2 million people aged 20–79 in SSA were estimated to have diabetes, representing a prevalence of 2.1–6.7%. (23) The region has the highest percentage of undiagnosed

cases of diabetes, with 66.7 % being unaware of their status. (24) The majority of individuals with diabetes (58.8 %) live in towns, although the population in the region (61.3 %) is mainly rural. With growing urbanisation and an ageing population, diabetes will pose an even greater threat. (24)

There are extensive international data, for example, from Europe (DECODE), Asia (DECODA), Australia and the USA reporting a steady increase in the prevalence of diagnosed and undiagnosed type 2 diabetes among patients as they grow older, with values reaching a plateau or even declining slightly – in the very old. (25-28) In addition, the prevalence of Impaired glucose tolerance (IGT) and impaired fasting glucose (IFG) both significant risk factors for the development of future diabetes, increase with age. (29)

2.3.3. Diagnosis and diagnostic criteria of diabetes in older persons

Current guidelines have a standard approach to the diagnosis and diagnostic criteria of diabetes. Table 2-3 shows latest WHO and International Diabetes Federation (IDF) criteria. The current cut-offs for the diagnosis of diabetes mellitus are ≥ 126 mg/dl (>7 mmol/l) for FPG, ≥ 200 mg/dl (≥ 11.1 mmol/l) for 2h-PG and $\geq 6.5\%$ (≥ 48 mmol/mol) for HbA1c. (30)

Table 2–3 1999 WHO criteria for the diagnosis of diabetes (values in (mmol l) (30)

Diagnostic category	Plasma glucose		Whole-blood glucose	
	Venous	Capillary	Venous	Capillary
Diabetes				
Fasting or	≥ 7.0	≥ 7.0	≥ 6.1	≥ 6.1
2-h post load	≥ 11.1	≥ 12.2	≥ 10.0	≥ 11.1
IGT				
Fasting and	< 7.0	< 7.0	< 6.1	< 6.1
2-h post load	7.8–11.0 (incl.)	8.9–12.1	6.7–9.9 (incl.)	7.8–11.0
IFG				
Fasting and	6.1–6.9 (incl.)	6.1–6.9 (incl.)	5.6–6.0 (incl.)	5.6–6.0 (incl.)
2-h post load	< 7.8	< 8.9	< 6.7	< 7.8

Two specific guidelines provide diagnostic criteria or diabetes in the older persons: the 2004 European Diabetes Working Party for Older People (EDWPOP) (31) and the 2013 International Diabetes Federation (IDF) (older people with type 2 diabetes). (32) In the first case, these criteria arose from the WHO consultation (1999) and the 2004 American Diabetes Association (ADA) Expert Committee criteria. Later, the 2011 EDWPOP (31) clinical guideline for type 2 diabetes reinforced the concept that diagnosis of diabetes in the older persons should be in accordance by

published national/international criteria and that no age-modified criteria could be recognised. In the second case, IDF criteria came from 2006–2011 WHO guidelines. (31)

2.3.4. Diabetes complications and multimorbidity in older persons

The terms ‘co-morbidity’, ‘multiple co-morbidity’, ‘multimorbidity’ and ‘multiple chronic conditions’ are used to define the presence of two or more medical conditions in the same patient and are very common in older persons, with more than half of them having three or more chronic conditions.(33–34) Diabetes is associated with extensive morbidity from macro- and micro-vascular complications. Known risk factors for these include duration of diabetes, glycaemic control and the presence of traditional risk factors such as smoking, hypercholesterolemia, and hypertension. (35) In older people with diabetes, the risk of macrovascular complications (cardiovascular disease, cerebrovascular disease, and peripheral vascular disease) is two-fold higher than in with controls(52).

Older persons with diabetes also have a higher prevalence of depression and impaired cognitive function when compared with age-matched controls without diabetes. (36) Depression in older persons with diabetes is a strong predictor of hospitalisation and death. (37–38) The changes in cognitive and affective function are closely correlated with lipid, blood pressure, and HbA1C values, and new studies suggest that improved glycemic control may enhance cognition and mood in this population group (39–41) Diabetes in older persons is a risk factor for vascular dementia and may also be a risk factor for Alzheimer's disease, though the latter is debatable. (42–44)

When there is a cognitive decline the complexity of managing diseases increases considerably. This, together with the paucity of clear evidence-based treatment guidelines for the older person with diabetes, presents a significant challenge to health care professionals (45–48) This is, in part, because evidence-based guidelines designed for younger people who have diabetes cannot be simply generalised for the use of older persons without considering problems, such as multimorbidity, functional impairment, frailty and the need to assess individual goals, including the quality of life. (48)

2.4. Part 3: Diabetes care in sub-Saharan Africa

The health systems in most SSA countries are overwhelmed by the complex challenge of dealing with a considerable burden of acute and chronic infectious diseases and poverty while also addressing the increasing burden of NCDs, including diabetes. Most of the healthcare financial resources of these countries are focused on infectious diseases, such as tuberculosis, malaria and HIV/AIDS.(49-50)

The Lancet Commission on Diabetes in Africa described an ‘inadequate availability of simple equipment for diagnosis and monitoring, a lack of sufficiently knowledgeable health-care providers,

insufficient availability of treatments, a dearth of locally appropriate guidelines, and few disease registries. Thus, access to diabetes care in SSA is not available to many of those who need it. As a result, people remain undiagnosed and those diagnosed with diabetes are frequently not receiving the advice and drugs they need. (51) Still more people diagnosed with diabetes suffer devastating consequences such as amputation and blindness. Yet diabetes can be controlled and even prevented through the resourceful implementation of health promotion interventions focused on diabetes self-management education/support programmes. (52)

2.4.1. Challenges of diabetes care in South Africa

South Africa is undergoing the epidemiological transition typical of many low-to-middle-income countries, where rapid urbanisation, attendant changes in diets and levels of physical activity along with increased longevity have resulted in a significant increase in the incidence of chronic diseases of lifestyle. Diabetes and hypertension are the most common chronic health conditions among older people. This phenomenon is occurring in the context of high HIV prevalence, with co-morbidity being particularly pronounced among older persons. (53) A large percentage (40%) of this population is poor and dependent on state support for their health and welfare needs. (53)

2.4.1.1. South African health care system

The system of healthcare in South Africa consists of a government-funded public sector and private sector that work in parallel, and together consume 8.5% of the National Gross Domestic Product (GDP) (54). The public health sector is responsible for the provision of care to about 84% of the inhabitants and accounts for 4.2% of GDP, whereas the private sector consumes 4.3% of the national GDP for 16.4% of the inhabitants. Roughly 25% of uninsured persons pay out of pocket for private-sector care. Annual per capita expenditure on health ranges from US\$ 1 400 in the private sector to about \$ 140 in the public sector. (54)

2.4.1.2. Health care services delivery for older persons in South Africa

The SA government provides free healthcare services to older people in the public health sector (which caters for the 84% of South Africans who cannot afford private health insurance). (55) There are three categories of healthcare facilities currently used by older individuals. First, primary healthcare services are free to all older persons and deal with the prevention and care of conditions or diseases (55). Primary healthcare tasks affecting older persons include health promotion activities, the identification of individuals suffering from common chronic conditions or illnesses related to ageing, and therapeutic services for common chronic conditions. (55) Then, secondary healthcare facilities are also free to all those older persons receiving a social grant. Tasks of secondary healthcare facilities to older persons include diagnosis and treatment, referral to specialist care and rehabilitating services, etc. Thirdly, tertiary healthcare services provide specialist

multi-disciplinary care for older persons with complex and multiple chronic conditions or diseases. (55)

The types of healthcare services generally used by older persons aged 60 years and older by province are summarised in Figure 2–3. Approximately 85% of older persons aged 60 years and older utilised public clinics in Limpopo, while more than 70% in the Eastern Cape, KwaZulu-Natal, North West and Mpumalanga also made use of this type of facility. The use of public (district) hospitals was most common in the Western Cape (20%), followed by KwaZulu-Natal (8.6%). Private hospitals/clinics/doctors were most likely to be used by older persons living in the Western Cape at 56.8 %, with Gauteng at 46.8% and the Free State at 34.2%.(6)

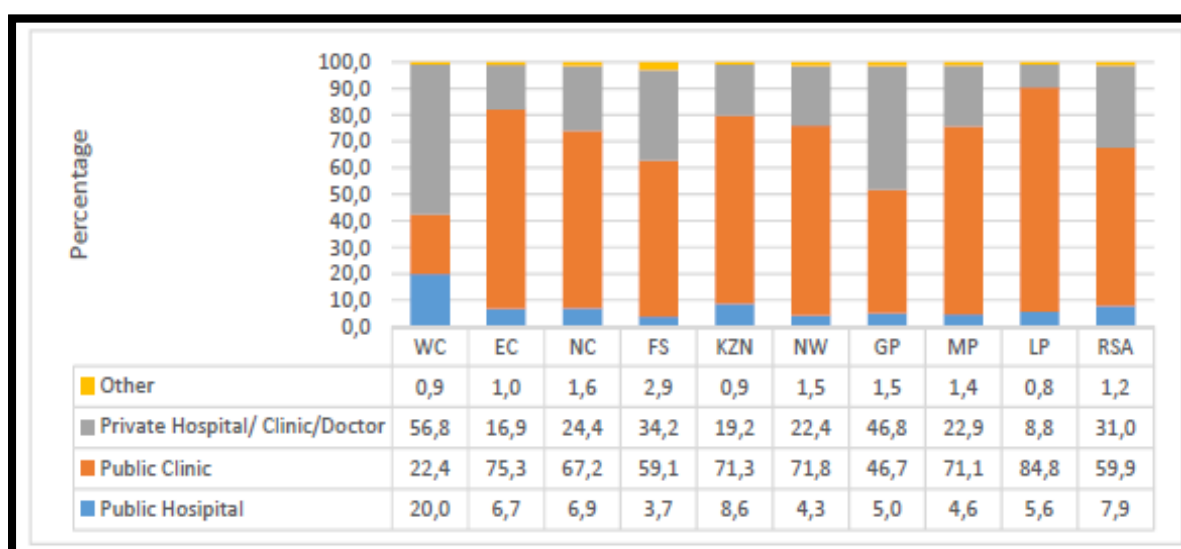


Figure 2–4 Types of health services used by older persons aged 60 years and older, by province, 2015 (6)

Primary health services in SA are predominantly clinic-based and focus on acute conditions and are not well suited to managing the growing burden of chronic disease. Numerous studies have illustrated that NCDs and their risk factors are infrequently diagnosed and inadequately treated at the primary care level, resulting in high levels of uncontrolled hypertension, diabetes, hyperlipidemia and chronic respiratory disease. (56) Importantly, access to care is often a challenge for older individuals due to the lack and/or cost of transport, particularly in rural areas, disability and child-caring responsibilities. Overcrowding and long waiting times at health facilities, fragmented or siloed care for multiple morbidities, and poor communication with healthcare providers are also commonly cited as barriers to care. (57)

Furthermore, the public health sector is not prepared to deal with the multifaceted needs of older persons with co-morbidity. For instance, in 2013 the National Health Facilities Baseline Audit reported (58) on a survey of 3 356 clinics and community health centres that found that most clinics had facility managers but nearly half of the clinics had no visiting doctors; 84% had no assistance

from a pharmacist or pharmacy assistant; 11% had no lay counsellors; 57% had no administrative support; and 79% had no information management staff. (58) In addition, given time and resource restrictions, fee structures and the typical nature of doctor-patient-relationship, many healthcare professionals, including private healthcare professionals, do not provide older persons with adequate care or struggle to identify frailty and dementia. (58)

There is little specialised training in geriatrics in South Africa and limited undergraduate exposure to geriatric syndromes in medical training (59) There are only a few departments of geriatrics that exist in South African academic medical facilities. Kalula et al. 2007 have criticised the current situation in South Africa, stating that ‘older persons care is not a priority in institutional planning and training curricula, and that most health professionals complete medical training without adequate exposure to geriatric medicine’. (60)

The Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) recently suggested that ‘[a] holistic individualised care plan for older persons, with the aim of sustaining independence should be sought’. (61) The increase in diabetes amongst disadvantaged people, including older persons, puts a massive demand for the provision of health education and diabetes care services on district hospitals and health centres and clinics. Therefore, practical guidelines and low-cost programmes for diabetes self-management education and support are importantly needed to assist them move from the hospital to the community. (61)

As shown in Figure 2–5, the WHO Innovative Care for Chronic Conditions Framework (ICCC) provides a robust platform for the development of such interventions in the healthcare system. (62) The ICCC model also suggests continuity and coordination of services between primary, secondary and tertiary care. This framework includes community, patient, healthcare and policy environment perspectives, and forms the foundation of South Africa’s primary health care re-engineering and strategic plan for chronic disease management integration. (62)

Regrettably, however, it does not significantly incorporate any complexity related to multimorbidity. Such complex multimorbidity is a key challenge to current SA models of healthcare delivery and there is a need to ensure integrated care across disease pathways and across primary and secondary health care services. (63–65) Foremost is the need for a shift to a patient-centred and more age-friendly approach to strengthening self- management. (66)

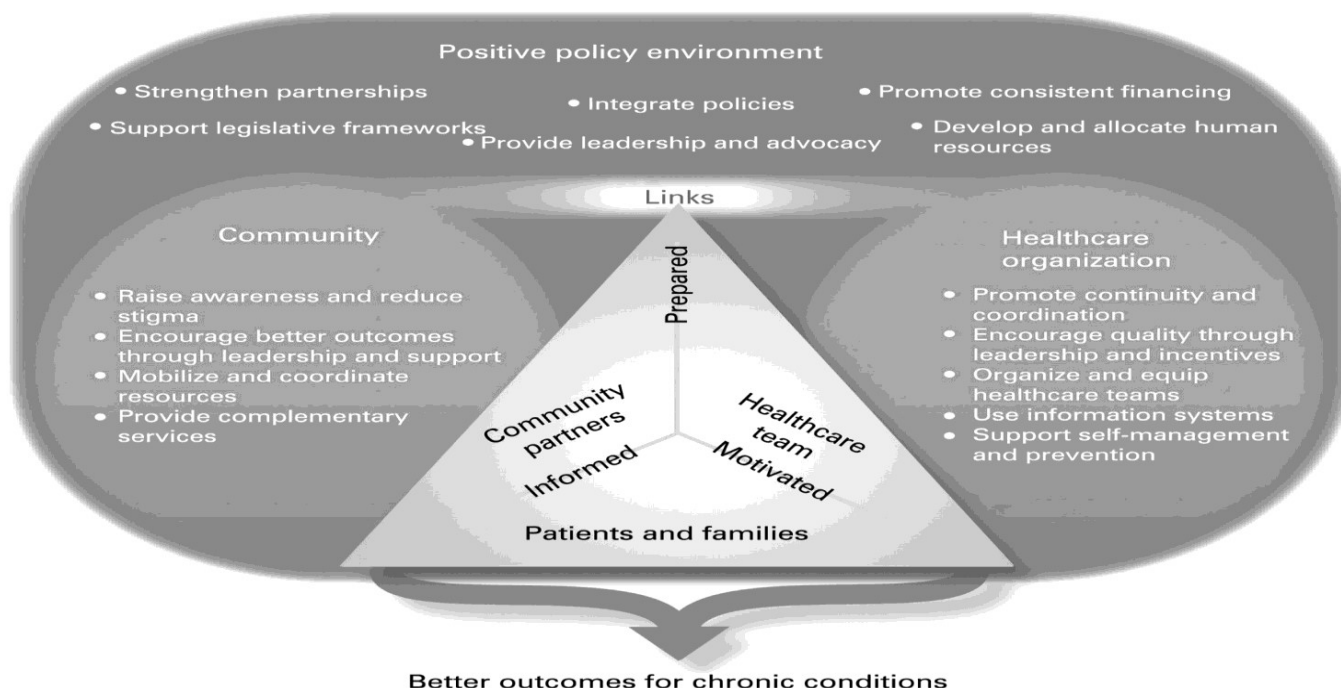


Figure 2–5 Innovative Care for Chronic Conditions Framework (ICCC) (62)

2.5. Part 4: Diabetes care models for older persons

There is increasing evidence that supporting individuals with long-term chronic conditions, such as diabetes, to care for themselves leads to improvements in clinical outcomes and in their health-related quality of life. Sinclair et al. (67) have suggested the principal goals of managing diabetes in older persons. The broad goals of diabetes management in older persons are not significantly different from those of younger individuals with diabetes. Controlling glycemia and management aimed at reducing the other risk factors for macrovascular and microvascular disease remain principal. However, diabetes care for older persons should be modified to a functional status, not to a co-morbid burden. (68–70)

Self-management, education, and empowerment are important cornerstones of diabetes care in all national and international diabetes guidelines, with an emphasis on self-management care and education. (71) Healthcare providers have been encouraged to engage with people in their care and decisions about their management plan that should encompass the needs, goals and life experiences of the person with diabetes. (71) Diabetes self-management education (DSME) provides knowledge and the skills needed for self-management care activities that aim for optimal health outcomes and quality of life. The objectives of DSME are to support informed decision-making, self-care behaviours and active collaboration with the healthcare providers. DSME is thus a critical component of care for all people with diabetes and is essential to improve patient health outcomes. (71)

2.5.1. Self-management care and support in older persons

It is appropriate to look at the concept of self-care in the light of the ageing population. The WHO defines self-care as ‘the activities persons, families, and communities undertake with the aim of enhancing health, preventing disease, limiting disease, and restoring health’.(72) This definition reflects the fact that self-care skills and knowledge stem from lay experience and suggests that self-care is a part of everyday living. Self-care may comprise behaviour and actions taken by those who are healthy, at risk of ill health, experiencing symptoms, diagnosed with a disease or receiving treatment. Therefore, it encompasses specific types of self-care, such as self-diagnosis, self-management, self-medication and self-monitoring. (73)

It is after the self-care ability for older persons has been identified that planning can be done to deal with their unmet needs. (74) It has been revealed that self-care and self-care education has the potential for saving the limited resources that older persons need to spend on healthcare and for enhancing healthcare resources. (75–76) Dean et al. (77) assume that the day-to-day management of diabetes is a routine regularly undertaken by the patient and supported by his/her family as well as the healthcare providers.

This is, however, not always the case. It is essential that self-care actions regarding the meanings attached to them and the context in which they take place, the norms they are subject to and the resources available to the individuals be understood. (78–80) Furthermore, self-management support expands the role of healthcare professionals from delivering information and traditional patient education to include helping patients build confidence and make choices that lead to improved self-management and better outcomes. (81) It comprises knowledge, skills and confidence to make daily decisions, select and make behaviour changes and cope with the emotional aspects of their sickness within the context of their lives. (82) Consequently, healthcare providers would be focused on the impact of ageing on self-care management capabilities and support their patients adjust self-care management to adapt to psychosocial and physiological changes associated with ageing. (83-86)

2.5.2. Diabetes self-management education for older persons

Older persons are under-represented in DSME research studies. As a result, the American Association of Diabetes Educators (AADE) and the American Geriatric Society (AGS) have formulated guidelines for DSME in the elderly, based mainly on expert consensus. (87-88)

At present, DSME in most African countries, including South Africa, is limited in scope, content and consistency and it is not clear how older persons manage their diabetes. (89–90) A recent systematic review described the level of self-management care among people living with type 2 diabetes in Africa. (91) In this review, 43 mostly observational studies met the inclusion criteria and

the authors concluded that 'diabetes self-management care in Africa is poor and therefore a serious threat to the health of people and the health systems capacity'. (91) This is because the studies demonstrated infrequent self-blood glucose monitoring (when this was available), low frequency or length of physical activity, moderate adherence to recommended dietary and medication behaviour, and a poor level of knowledge of diabetes-related complications. The review also found that the studies did not address psychosocial aspects. (91) Questions remain, also, about the effectiveness of diabetes self-management care and educational/behavioural interventions for older diabetes persons, primarily regarding how normal cognitive decline and increased co-morbidities related the impacts of ageing and self-management care of diabetes in everyday life. What has, for example, not been studied optimally is the presence of complications and co-morbidities accompanying the aging process' as well as how essential specific self-management care practices have been adapted to meet the needs of the elderly. (92)

2.5.3 Self-management care challenges in older persons

Self-management care and its maintenance among older persons with type 2 diabetes is challenging and demanding. Assessment of self-management ability must be evaluated from time to time during health-care provider and patient interaction. (93) According to the WHO, the best choices to avoid complications in low-resource settings (94) lie in the monitoring of blood sugar and checking the risk of cardiovascular disease (CVD) by counselling to promote a healthy life with diet, exercise and medicines. However, diabetes management must be carried out by both the individual affected by diabetes and by involving health care providers, through self-management care and altered behaviours. The latter includes, for instance, self-monitoring blood-glucose, diet and physical activity adjustments. Furthermore, diabetes self-management care must be individualised to best suit the diabetes goals of the diabetic. (95) Other components of self-management care in older persons that need attention include polypharmacy, depression and cognitive impairment. Consequently, interventions to best address management and education for older persons with diabetes are required. (95)

In the next sections, the challenges faced by older persons in achieving optimum levels of knowledge and the skills needed for their self-care activities are discussed.

2.5.3.1. Eating healthily

Diet is a vital component of diabetes care for all ages, while nutritional guidelines do not differ for younger versus older persons, older individuals with diabetes may present with unique challenges that influence their ability to follow a healthy diet. (96) Older persons may be at risk for malnutrition due to cognitive dysfunction, depression and functional impairments leading to difficulties in making or consuming food. Notably, nutrition recommendations should consider the older individual's unique culture, values, preferences, and individual goals and abilities. (97) Nutritional education

has been shown to improve glycaemic control. For example, in a study by Redmond et al., (98) the impact of nutrition education sessions intervention on older individuals was evaluated. They found that, following the intervention, the mean change in HbA1c levels for all participants decreased $0.24 \pm 1.35\%$ ($p=0.11$). Moreover, Chelbowy et. al. (99) demonstrated that older African-American females with T2DM complained of a lack of self-control related to diet restrictions, particularly at holiday and family parties. Importantly, they also found that social support was statistically significant in following a diabetes diet ($p=0.01$). All participants, however, stated that 'they believed healthy diet was best for the body though at the same time stated they were too expensive, so they did not eat adequate healthy foods'. (99)

2.5.3.2. Being active

Although age and diabetes conspire to diminish fitness and strength, there are data indicating that lifestyle interventions may be beneficial to this group. In an Action for Health in Diabetes study, although subjects aged 65–76 years had lower gains in fitness with the rigorous lifestyle intervention than younger participants, they still improved their measures of fitness by a mean of over 15%. (100) In older persons, even light-intensity physical activity is linked with higher self-rated physical health and psychosocial well-being. (101)

Older individuals with diabetes who are otherwise healthy and functional should be encouraged to exercise to targets recommended for all adults with diabetes. (102) An eight-year prospective study of adults with diabetes ($n = 2896$) showed that those who had walked for two hours per week had a 39% lower all-cause death rate and a 34% decrease in CVD-related deaths. Notably, the size of these effects persisted after controlling for multiple factors. These included age, gender, obesity, functional limitations and other co-morbid conditions. (103)

2.5.3.3. Medication adherence and polypharmacy

A systematic review on older persons and medication adherence emphasised the issue of multimorbidity and polypharmacy and thus an increased likelihood of their mismanaging their medication (104). Furthermore, older individuals may ration the administration at the lowest possible dose rather than the prescribed dose – something which in diabetes management could have significant implications for glycaemic control and the potential for developing more complications. (105) Rhee et al., (105) using a retrospective assessment in $n=1560$ older individuals, highlighted that glycaemic control improved progressively with greater medication adherence and 1 263 subjects were between 76%-100% adherent. However, these findings must be viewed with caution, as the benefits of medication adherence may have been confounded by the associated impact of adherence to diet, self-monitoring of blood glucose (SMBG) and exercise.

2.5.3.4. Cognitive impairment

Older persons with cognitive impairment using insulin were significantly more likely not to know what to do in the setting of hypoglycemia and gave more incorrect answers when asked about diabetes management than those who were intact cognitively. Cognitive impairment may result in older individuals being less able to monitor their blood glucose levels, inject insulin (106) or adhere to their oral medication regimen.

2.5.3.5. Depressive symptoms and distress

The relationship between diabetes and depression seems to be bidirectional. In the Health, Aging, and Body Composition Study, where older persons (70–79 years) with diabetes showed an increased prevalence of depression compared with persons without diabetes (23.5% vs 19.0%, hazard ratio (HR) 1.31, 95% confidence interval (CI) 1.07–1.61). (107) In a meta-analysis of 16 studies to analyse the risk of depression associated with diabetes, both the relative risk (RR) and HR were significant at 1.27 (95% CI 1.17–1.38) and 1.23 (CI 1.08–1.40) for incident depression associated with diabetes. (108) It has been suggested that healthcare providers should actively look for symptoms of depression as older individuals with co-morbid diabetes and depression are willing to discuss their glycemic control but are reluctant to discuss their depressive symptoms and its effects on self-care. (109)

2.5.3.6. Self-monitoring of blood glucose (SMBG)

Some family members may need education about how to undertake diabetes self-management care tasks such as SMBG and administering insulin to enable them to support the person with diabetes. (110) However, the value of SMBG in people with T2DM is not proven, particularly in those not using insulin. (111–113)

To summarise, understanding the impact of the abovementioned challenges on diabetes self-management care is critical for improving diabetes treatment in older persons. The promotion of a healthy lifestyle with diet, exercise and adherence to prescribed medication is the best options to avoid complications and improve quality of life. Support for older individuals to stay in their households for as long as possible is provided through health promotion activities which focus on self-care management education and support.

2.6. Part 5: Theories and models for health promotion

This section aims to provide a brief overview of the literature on various theoretical models of health promotion. Over the past three decades, the body of research in health behaviour has grown fast, and health education and health promotion are documented increasingly as ways to meet public health objectives and improve the success of public health and medical interventions globally. (114)

Programmes to impact health behaviour, including health promotion and education programs, are most likely to benefit participants and communities when a theory of health behaviour guides the programme or intervention. Hubley et al. stated that ‘when we speak of the adaption and maintenance of attitudes and behaviours identified to promote health and well-being’ for older individuals, evidence-based health promotion programmes tailored to a specific community’s needs and context is what is discussed. (115-116) In a debate on health promotion and ageing, Haber et al. (117) commented on the lack of age specificity in health promotion models and proposed that a model of health promotion for older persons need the following components: ageing, communication and collaboration, health behaviour change, health education, diversity and advocacy.

2.6.1 Theories and models

Theories of health promotion identify the targets for change and the methods for achieving these changes. Theories also inform the assessment of change efforts by helping to identify the outcomes to be measured, as well as the timing and methods of study to be used, (118) and these fall mainly in three categories: 1. Individual level: Behaviour modification; the Health Belief Model; the Transtheoretical Model; Lay Beliefs; 2. Interpersonal level: the Theory of Reasoned Action; Social Learning Theory; 3. Theoretical frameworks with multiple levels: an ecological model; the PRECEDE-PROCEED model. (118) The key elements of these approaches are listed in (Table 2–6).

Table 2–4 Key elements of theoretical models of health promotion (118)

Theory	Elements
<i>Individual-level theories</i>	
Behaviour modification	Shaping behaviour Reinforcement
Health Belief Model	Perceived severity, Perceived susceptibility Perceived benefits, Perceived barriers Cues to action, Self-efficacy
Transtheoretical Model (Stages of Change)	Precontemplation, Contemplation Determination or preparation, Action, Maintenance
<i>Interpersonal level theories</i>	
Theory of Reasoned Action	Intentions to perform an action, Attitude toward the behaviour Subjective norm, Volitional control
Social Learning Theory (Social cognition)	Self-efficacy, Outcome expectations, Modelling, Social support Reinforcement, Self-monitoring
<i>Theoretical frameworks /Planning models — multiple levels</i>	
PRECEDE-PROCEED Model	Social diagnosis, Epidemiological diagnosis, Behavioural and environmental diagnosis, Educational and organisational diagnosis, Administrative and policy diagnosis Implementation, Process evaluation, Impact evaluation, Outcome evaluation
Ecological model	Intrapersonal factors, Interpersonal factors, Institutional factors, Community factors Public policy

2.6.2. Individual level theories

Individual level theories generally are most appropriate for addressing predisposing factors. They help planners identify messages for direct communication methods such as mass media and face-to-face education, as well as for newer technologies such as computer tailoring of health messages. (118) These theories also involve the health-decision model that endeavours to describe health decisions and resultant behaviour; the self-regulation model based on the locus of control theory; social cognitive theory, with self-efficacy as its core component; and a model of disease self-management based on self-regulation of what is useful and what is not for the individual, given their specific goals. (119)

2.6.3. Interpersonal level theories

Interpersonal level theories are most appropriate for reinforcing factors, and they suggest indirect communication channels (for example, through significant others, social networks) and methods (for instance, train-the-trainer models, social support enhancement). Community level theories are appropriate for enabling factors, and they suggest environmental changes (for example, organisation and delivery of services; availability of policies; and regulations that govern behaviours) and methods such as community organising and advocacy. (120)

2.6.4. Programme and strategy planning models — multiple levels

Planning models recognise the complexities of health behaviour. These are more consistent with a broad definition of health promotion that recognises the impact of many factors on health and health behaviours. These models are much broader than theories and, as such, are inclusive of theories. (120) They educate the practitioner about which theory or theories should be used and when and how they should be applied. (121) A particularly useful, widely applied, and easy-to-follow example of a planning model is the PRECEDE-PROCEED (PPM) planning model.

2.6.4.1. The PRECEDE-PROCEED planning model.

The PRECEDE-PROCEED model for health programme planning and evaluation is broadly taught and used in health promotion practice, with well over 1 000 published applications. (122) The PRECEDE framework was first described in the 1970s and subsequently revised in 2005 to respond to the growing interest in ecological and participatory methods that have become more widely appreciated as crucial elements of public health programmes. The PRECEDE-PROCEED planning model provides an eight-phase framework for health care professionals to determine, develop, implement and assess health promotion programmes, as well as the application of health promotion theories systematically within such programmes. (122). The PRECEDE-PROCEED model has four assessment and planning phases to direct the health professionals in selecting what health problem to address, examining its underlying causes, and planning an intervention (Figure 1–5). (122)

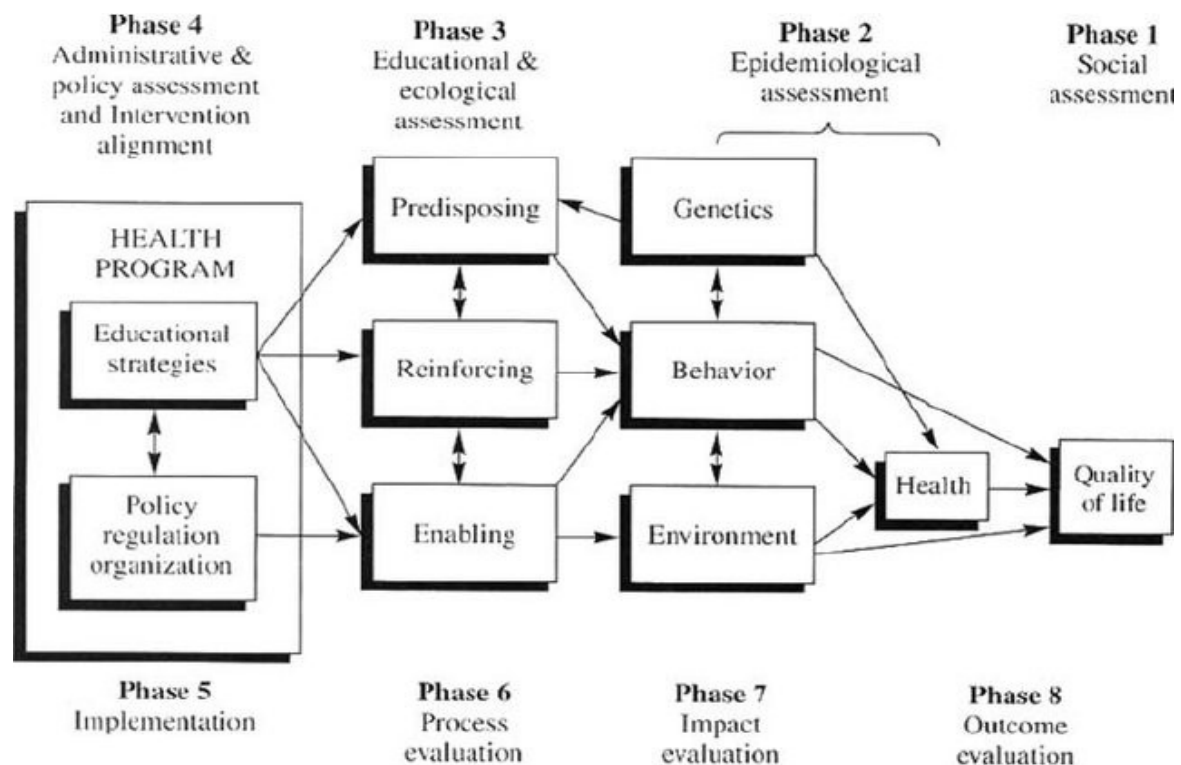


Figure 2–6. The Precede-Proceed model. From Green and Kreuter 2005 (122)

Phase 1: Social assessment

The social assessment identifies and evaluates potential areas for health action, through engaging the community in this diagnosis, using both objective and subjective information from many sources, the goal is to recognise the individual's priorities in improving their quality of lives (122) It commences with a systematic and inclusive assessment of the participants' social situation, with a clear emphasis on their self-perceived quality of life and the resources accessible to them that contribute to the health and health-related quality of life. Hence, this phase aims to attain insights into the social conditions of the participants and as well to assess their general hopes and health beliefs. Typically, this phase explores the participants' health-related needs and their general assumptions and goals for health and life. This process reveals social indicators that may compete with, or contribute to, the person's quality of life.(122)

Phase 2: Epidemiological assessment

The epidemiological assessment recognises and prioritises health issues and sets change objectives by : (1) identifying the health problems, issues, or aspirations on which the programme will focus; (2) uncovering the behavioural and environmental factors most likely to influence the identified priority health problems; and (3) translating those priorities into measurable aims and objectives for the programme being developed. (122)

Phase 3: An educational and ecological assessment

After selecting the relevant behavioural and environmental factors for the programme, the framework guides planners to recognise the antecedent and reinforcing factors that should be in place to initiate and sustain the change process. These factors are classified as predisposing, reinforcing, and enabling and together they influence the behavioural and environmental change that will occur. (122)

Predisposing factors: are antecedents to behaviour that provide the justification or motivation for the behaviour, they comprise individuals' knowledge, attitudes, beliefs, personal preferences, existing skills, and self-efficacy beliefs.

Reinforcing factors: are those factors following a behaviour that provide continuing reward or incentive for the persistence or repetition of the behaviour. For instance social support, peer influence, significant others, and vicarious reinforcement.

Enabling factors: are antecedents to behavioural or environmental change that allow a motivation or environmental policy to be realised. Enabling factors can affect behaviour directly or indirectly through an environmental factor. They involve programmes, services, and resources necessary for behavioural and environmental outcomes to be realised and, in some cases, the new skills required to enable behaviour change. (122) It should be possible by the end of Phase 3 to select, sort and categorise the predisposing, reinforcing and enabling factors regarding their impact and potential to change health behaviour patterns. The outcome is a cascaded mapping of predisposing, reinforcing and enabling factors, in the order of their impact on behaviour and their subsequent effects on health and quality of life. (122) After this, targets for the health-promotion programme can be identified.

Phase 4: Administrative policy and intervention-alignment assessment

Green and Kreuter also recommend conducting an internal policy assessment within the planning organisation to confirm policies align with the proposed programme plan and to measure political forces likely to impact implementation. (122)

Phases 5–8: Implementation and assessment

Phases 5 to 8 of the model are not relevant to this study and will be only briefly discussed here. At this stage, the health promotion programme is prepared for the implementation phase (Phase 5). Data collection plans should be ready for assessing the process, impact, and outcome of the programme, which are the last three phases in the PPM. Usually, process evaluation determines the extent to which the programme was implemented according to the protocol. Impact evaluation assesses changes in predisposing, reinforcing, and enabling factors, as well as in the behavioural

and environmental factors. Finally, outcome assessment determines the effect of the programme on health and quality-of-life indicators. (122-)

2.7. Chapter summary

The literature review has highlighted that population figures of older persons have been growing globally and particularly in SSA/SA. It is projected that in SA the proportion of its population aged 60 years or older will increase from 7.2% to 15% of the total population over the next 35 years. As the prevalence of diabetes increases with age there will be an increase in the current high demand on health systems for the prevention and treatment of diabetes and its associated complications. There are major limitations to access to quality diabetes care in SSA and even in SA. There is little specific research in SA/SSA relating to diabetes in older people, and in the assessment and diagnoses of the related co-morbidity., The research designs and methods including needs assessment for this study are discussed in the following chapter.

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Chapter 3

Research design and methods

3.1. Chapter outline

This chapter outlines an overview of the application of the PRECEDE-PROCEED model in general. As the methods are discussed in detail in each of the five papers, a brief overview is provided in this chapter.

3.2. Research Design

A needs assessment is a critical element of planning a programme as it identifies, scrutinises, rationalises and selects gaps or deficiencies to be closed. (1) This research study is based on the theoretical framework of the PRECEDE-PROCEED model (PPM). (2) In the PPM, a complete needs assessment involving phases should be made before planning a health promotion intervention. Due to the limited resources available for the present body of work, only the PRECEDE four phases (Phase 1 to Phase 4) were completed. This study sets out to fill the current gaps in knowledge of diabetes in the older person in South Africa, with a view of developing a diabetes self-care management programme targeted at this group and therefore limiting the impact of the disease and improving their health-related quality of life. The following section briefly describes the conducting of the needs assessment within the theoretical framework of the PRECEDE-PROCEED model.

3.2.1. Applying the PRECEDE component of the PRECEDE-PROCEED model

In this study, the needs assessment was conducted in four steps as seen in the accompanying figure. 3-1. In Phase 1, the social assessment, the relationship between health and social issues is considered. The planner identifies a target population's social priorities which, in turn, reflect that population's quality-of-life priorities. To achieve this objective a survey was conducted to assess the association between diabetes and health-related quality of life and disability amongst South Africa's older persons, as well as whether associations between other factors and these measures of well-being differed between older individuals with diabetes and those without (study 2).

The task of the planner in Phase 2, the epidemiological assessment, is to recognise the specific health goals or difficulties that may contribute to the social goals or concerns identified in Phase 1. Objective indicators such as demographic patterns of health problems are used to ascertain how specific health problems are related to the subjectively appraised quality-of-life. Frequently, a

specific health problem such as diabetes has already been recognised as a priority by the target population, health professionals, or policymaker. In such cases, the program planning researcher begins with Phase 2 but must work back. This approach is adopted by looking at how the specific problems of diabetes are related to the broader health and social context of older individuals in Africa including South Africa. The task of the researcher in this phase is to recognise the specific health goals or difficulties that may contribute to the social goals or concerns identified in Phase 1. For pragmatic reasons the epidemiological assessment was limited to a systematic review of the prevalence of type 2 diabetes mellitus among older people in the African continent to understand the extent of the burden on the continent (study 1) and presented in this thesis as (Chapter 4)

In Phase 3, the educational and organisational assessment, the researcher evaluates the relationship between those factors that determine the behavioural and environmental objectives set in Phase 2. These may be grouped into three broad classes: predisposing, enabling, and reinforcing factors that influence behavioural or environment. Phases 2 and 3 result in the formulation of clear behavioural and environmental objectives for the program, and the educational and organisational strategies to be employed. To achieve those objectives, the researcher conducted a cross sectional survey exploring the status of knowledge, self-management practice, and social support, as well to determine the relationship of social support, especially that of family and friends with their self-management for South African older persons with type 2 diabetes (study 3).

Phase 4, the administrative and policy assessment and Intervention Alignment, marks the shift from the planning phases (PRECEDE) of the model to the action phases (PROCEED). When creating the programme plan, it is imperative to look at two levels of alignment between the assessment of determinants and the selection of interventions. First, at the macro level, the organizational systems that can affect the desired outcomes should be considered. Second, at the micro level, the focus is on individual, peer, family, and others who can influence the intended individuals health behaviors more directly. The researcher limited this phase to Steps A and B, studies 4 and 5 respectively. . Step A (Study 4), an administrative and policy assessment involved a documentary review and interviewing key informants to obtain an in-depth description of current policies and practices relating to diabetes self-care management for older persons in South Africa. Step B (study 5), a systematic literature review which examined the effectiveness of existing peer and non-professional health worker-led diabetes self-management programmes in primary health care settings in LMICs and examined the implementation strategies and associated diabetes-related health outcomes.

3.3. Justification of mixed method design choice in this thesis

The methodological choice in this thesis is to use mixed methods research where the quantitative and qualitative methods are combined. (3) The rationale for mixing is that neither quantitative nor qualitative methods alone are sufficient to capture the trends nor the details of the situation, such as the complex issue of self-management care that targeted older persons in their dwellings and in a community healthcare setting. The thesis is organised so as to present the quantitative studies first, and follow these with a discussion of the qualitative study and the integration of the two approaches. (4–6)

3.4. Justifications for using systematic reviews

The decision for using systematic reviews (7) in this thesis is based on two critical issues. First, systematic reviews are recognised as an essential method for facilitating evidence-informed policy and practice because of their capacity to synthesis the results from multiple studies. (8) Secondly, there is a scarcity of data and methodological limitations around existing work within the field of research on diabetes self-management care for older persons within the chosen setting. (9)

3.3. Methodology of different phases/studies of the research study.

As has been noted in Figure 3–1, the sequence of the methodological approaches used in this research study are as follows:

3.3.1.Phase 1: Social assessment

Study 2: Diabetes in South African older adults: prevalence and impact on their quality of life and functional disability – as assessed using SAGE Wave 1 data.

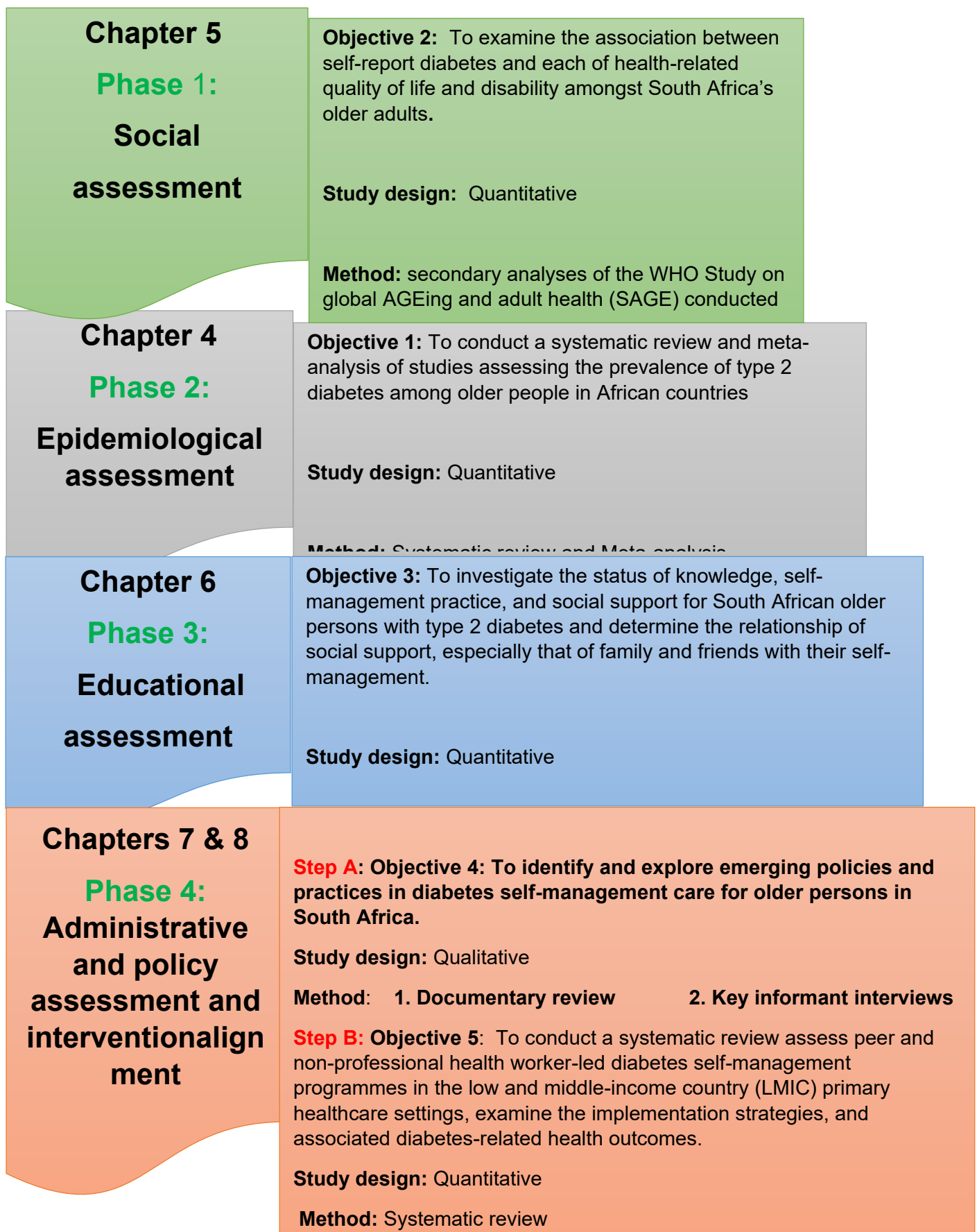


Figure 3-1. The flowchart shows the different phases of the PRECEDE model used in the study

Methods

Secondary analyses of data on 3 836 participants aged 50 years and older from the Study on global AGEing and adult health (SAGE) in South Africa Wave 1 (2007–2008) were conducted. (10)

Face-to-face interviews using a standardised questionnaire were used to collect information on socio-demographic characteristics, disability, subjective well-being, and other health measures and behavioural risk factors. The prevalence of self-report diabetes was first assessed. Then the association between diabetes and each of the WHO Quality of Life (WHOQoL) and WHO Disability Assessment Schedule (WHODAS) scores was examined with a control for selected socio-demographic characteristics, health risk behaviours and the presence of co-morbid conditions. The regression models were used to assess whether diabetes moderates the relationships between these additional factors and WHOQoL/ WHODAS. (10)

3.3.2. Phase 2: Epidemiological assessment

Study 1: The prevalence of type 2 diabetes among older people in Africa: a systematic review and meta-analysis

Methods

A comprehensive search of PubMed/MEDLINE, CINAHL, and Google Scholar was conducted for cross-sectional or population-based diabetes prevalence studies in Africa published from 1 January 2000, to 30 June, 2015, using the African search filter developed by Eisinga and colleagues and a range of search terms. Publications by key authors were also sought with citation searches on the websites of WHO and the IDF, the latter for the STEPwise approach to surveillance (STEPS) studies in Africa. No language restrictions were applied. The diagnosis of diabetes had to have been made by a physician or defined based on measured fasting plasma glucose (FPG), and the oral glucose tolerance test (OGTT). The full review protocol was published in a peer-reviewed journal (<https://bmjopen.bmj.com/content/4/6/e004747>) (Appendix 1). (11)

3.3.3. Phase 3: Educational and ecological assessment

Study 3: Does social support affect knowledge and diabetes self-management practices in older persons with type 2 diabetes attending primary care clinics in Cape Town, South Africa?

Methods

This cross-sectional study was undertaken in the Cape Town Metropole primary care clinics. The sample comprised 406 people drawn from four community health centres (CHC) served by Groote Schuur Hospital at the tertiary level. The 100 participants were selected from each selected community health centre by a random sampling technique with as near an equal distribution of

males and females as possible.

Fieldworkers administered a questionnaire to the participants in their home language to obtain sociodemographic and medical history data as well as information on diabetes knowledge, self-management practice and social support. The fieldworkers also reviewed the participants' clinic records for HbA1C and fasting blood glucose results. Signed consent to participate in the study was obtained before the administration of the study questionnaire.

3.3.4. Phase 4: Administrative and policy assessment and intervention alignment

Step A of Phase Four:

Study 4: A review of current policies and practice for the provision of diabetes care and self-management support programmes for older South Africans

Methods

These involved 2 steps. The first, a documentary review of relevant policies, plans, clinical guidelines and commentaries; and the second, interviews with key informants in the health services and Department of Health to get their perspectives on the current situation and the potential for a self-management programme tailored to the needs of older patients. The interviews were about 30 to 45 minutes in duration and were conducted from December 2016 to April 2017. They were audio-taped, transcribed verbatim and analysed using the method of qualitative content analysis.

Step B of Phase Four:

Study 5: The effectiveness of peer and community health worker-led self-management support programmes for improving diabetes health-related outcomes in adults in low-and-middle-income countries: A systematic review

Method

A literature search was conducted using the Cochrane Library, MEDLINE via PubMed, SCOPUS, CINAHL, PsycINFO, and Web of Science databases for studies published between 1 January 2000 and 31 December 2017 which evaluated community-based peer and community health worker-led diabetes self-management programmes (COMP-DSMP) in adults with diabetes in LMICs. Randomised and non-randomised controlled trials with at least three months follow-up and reporting on a behavioural, a primary psychological, and/or a clinical outcome was included.

In addition, the implementation taxonomy frameworks by Proctor et al (12) were used for analysis and evaluation of the implementation strategies used in the included studies.

This review is registered with the International Prospective Register of Systematic Reviews [registration number CRD42014007531]. Although the protocol was published in 2015 (Appendix

2) (13) (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4513536/>), the final methods used for the review were revised and the changes detailed in the methods section of (Chapter 8).

3.6. Data collection and analysis of the research study

Due to the variety of data collected in this research study, both descriptive statistical and appropriate qualitative approaches were used for data analysis. These approaches will be discussed within the following individual studies chapters.

3.7. Ethics approval

This research study was approved by the Human Ethics Committee of the University of Cape Town. HEC REF: 21/2013) and was conducted in accordance with the Declaration of Helsinki of 2013. Written consent was obtained from each participant (Appendix 3).

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Chapter 4

Study 1: The prevalence of type 2 diabetes among older people in Africa: a systematic review and meta-analysis

Role of the candidate

I, together with Professors Levitt, Engel and Kengne, was responsible for designing the protocol of the study. I did the literature search selected the studies, evaluated risk of bias and extracted the relevant information. I managed and cleaned the data and prepared it for analysis. I carried out the analyses, supported by Professor Andre Kengne. I drafted the manuscript, incorporating input from co-authors and I was responsible for finalising the final version of the manuscript for publication.

Role of the co-authors

MW, MEE, APK, and NSL designed the study. Dr Alfred Musekiwa (AM) independently selected the studies and extracted the relevant information. All authors synthesised the data. I wrote the first draft of the paper. MEE, APK, and NSL provided critical guidance on the analysis and overall direction of the study. All authors critically revised successive drafts of the paper and approved the final version.

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<https://bmjopen.bmj.com/content/bmjopen/4/6/e004747.full.pdf>.

4.1 Abstract

Little information is available on the prevalence of diabetes in people aged 55 years or older living on the African continent. We did a systematic review of the prevalence of type 2 diabetes in studies reported from Jan 1, 2000, to June 30, 2015, to provide accurate data for monitoring future trends. We did a comprehensive literature search using an African search filter and extracted and synthesised data from full papers.

Among 1473 identified citations, 41 studies providing 49 separate data contributions involving 16 086 individuals met the inclusion criteria. The overall prevalence of diabetes was 13·7% (95% CI 11·3–16·3) and was higher in studies based on the oral glucose tolerance test (23·9%, 17·7–30·7, 12 contributions with 3415 participants) than fasting blood glucose criteria (10·9%, 8·9–13·0, 37 contributions with 12 671 participants; $p<0\cdot001$). Prevalence was also higher in non-STEPS than in STEPS studies (17·1%, 95% CI 13·6–20·9) vs 9·6%, 6·6–13·0, $p=0\cdot003$) and in urban than in rural settings (19·7%, 15·0–24·9 vs 7·9%, 4·6–12·0, $p=0\cdot0002$), but did not differ significantly across age groups, sex, sample size, year of publication, region, or population coverage. These data highlight the need to reduce diabetes risk factors and implement adequate management strategies. In addition, we suggest that uniform diagnostic methods should be used across African countries and elsewhere to enable the assessment of trends in diabetes prevalence and the success of diabetes prevention strategies. A collaborative initiative is required between key international and national diabetes and geriatric organisations to improve diabetes care for the older population in Africa and worldwide.

4.2. Introduction

The International Diabetes Federation (IDF) estimated prevalence for type 2 diabetes in 2013, showed that the number of people affected worldwide has doubled over the past 20 years. Most (80%) live in low-income and middle-income countries. (1) In Africa, where all countries fall into these economic categories, diabetes already contributes substantially to morbidity and mortality, and the age-specific mortality rate is the highest in the world. (2–7) The rise in the number of individuals with type 2 diabetes in Africa, which is similar to that which has occurred in low-income and middle-income countries elsewhere in the world, has been attributed to ageing of the population and rapid change in environmental factors, (2) such as urbanisation, increasingly sedentary lifestyles, and unhealthy eating patterns. Although behaviour patterns and obesity can potentially be modified, ageing, which is one of the main drivers of diabetes, cannot. (3) In 2013, most individuals with diabetes in Africa were younger than 60 years, and the highest proportion (43·2%) comprised people aged 40–59 years. The small proportion of people aged 60–79 years in the region probably accounted for the fact that only 18·8% of people with diabetes fell into this age group. (1) Africa is often referred to as the youngest continent, which might contribute to the low prioritisation of ageing issues in national policies. (8) Yet the annual growth rate of people older than 55 years in Africa was estimated to be 3·1% greater than the global average between 2007 and 2015 and is predicted to be 3·3% greater between 2015 and 2050.

Thus, there are around 64·5 million people in Africa aged 55 years or older in 2015, and there are likely to be more than 103 million and 205 million in 2030 and 2050, respectively. (7) Consequently, the diabetes prevalence in Africa is expected to be highest in the oldest individuals by 2035. (1) We did a systematic review to investigate the prevalence of type 2 diabetes in Africa in individuals older than 55 years, with the aim of providing accurate data for monitoring of future trends.

4.3. Methods

4.3.1. Literature search

We aimed to identify prevalence studies in Africa published from Jan 1, 2000, to June 30, 2015, with use of the African search filter developed by Eisinga and colleagues. (9) The filter comprises African country names and truncated terms, such as “north* Africa”, to ensure that records indexed with regional rather than country-specific terms are also retrieved. We combined database medical subject headings (MeSH in PubMed / MEDLINE, CINAHL, and Google Scholar) with a range of search terms (Appendix 1).

African country names were included in English and languages applicable to each country, for example ‘Ivory Coast’ and ‘Côte d’Ivoire’. Where country names have changed over time, old and new names were included, such as ‘Zaire’ and ‘Democratic Republic of Congo’. (10) We searched

for publications by key authors with citation searches on the websites of WHO and the IDF, the latter for the STEPwise approach to surveillance (STEPS) surveys studies in Africa.

The panel shows the basic concept, framework, and key goals of STEPS surveys. (11,12) We also searched the ISI Web of Knowledge. No language restrictions were applied. An expert librarian designed the search strategy framework and applied the appropriate bibliographic software.

Panel: Basic concept, framework, and key goals of the WHO STEPwise approach to surveillance (11,12).

The STEPwise approach to Surveillance (STEPS) is WHO's recommended a tool for surveillance of chronic non-communicable diseases and their risk factors. It aims to provide an entry point for low-income and middle-income countries to start chronic disease surveillance. It is also designed to help countries build and strengthen surveillance capacity. In all instances, STEPS targets adults aged 25–64 years and uses a representative sample of the study population, which allows generalisation of the results to the whole. STEPS has some flexibility, which enables each country to expand on the core variables and risk factors and to incorporate optional modules relevant to local or regional interests.

The STEPS instrument has three different levels (or steps), all of which have core, expanded, and optional modules of risk factor assessment that are used depending on what can be accomplished in a given country. Step 1 uses a standardised questionnaire to gather demographic and behavioural information (tobacco and alcohol use, nutrition, and physical activity) in a household setting. Several extended options can be obtained, such as for demographics, ethnic origin, employment status, and household income; for behaviour, binge drinking, smokeless tobacco, and ex-smokers; and for diet, oil and fat consumption. Optional factors include mental and oral health and objective measures of physical activity.

Step 2 contains simple physical measurements to assess anthropometry and blood pressure, which can also be obtained in the household setting (heart rate, hip circumference, and [optional] skin-fold thickness and physical fitness). Step 3 consists of biochemical measurements: “fasting blood sugar” is the core measurement; the extended tests include measurement of total cholesterol, HDL-cholesterol, and fasting triglycerides; and optional tests are the oral glucose tolerance test, urine examination, and measurement of salivary cotinine to assess tobacco intake.

To be included in this systematic review, primary studies had to have used cross-sectional or population-based designs to assess the prevalence of type 2 diabetes among older adults (described in the report as older adults, or at least 70% of the study population aged 55 years or older) who were resident in countries in sub-Saharan or North Africa, irrespective of ethnic, socioeconomic, and educational backgrounds. The diagnosis of diabetes had to have been made by a physician or defined based on measured fasting plasma glucose (FPG), oral glucose tolerance test (OGTT), or self-report, according to WHO criteria (13). Studies had to report numeric data to

enable the calculation of prevalence. Those that used denominator data from other studies to calculate prevalence were excluded. Full-text articles identified as meeting the inclusion criteria on the basis of their titles and abstracts were obtained for further assessment by two reviewers (MW and AM), and those that did not meet the selection criteria were excluded (Figure 4–1). Disagreements were resolved through discussions between reviewers until consensus was reached.

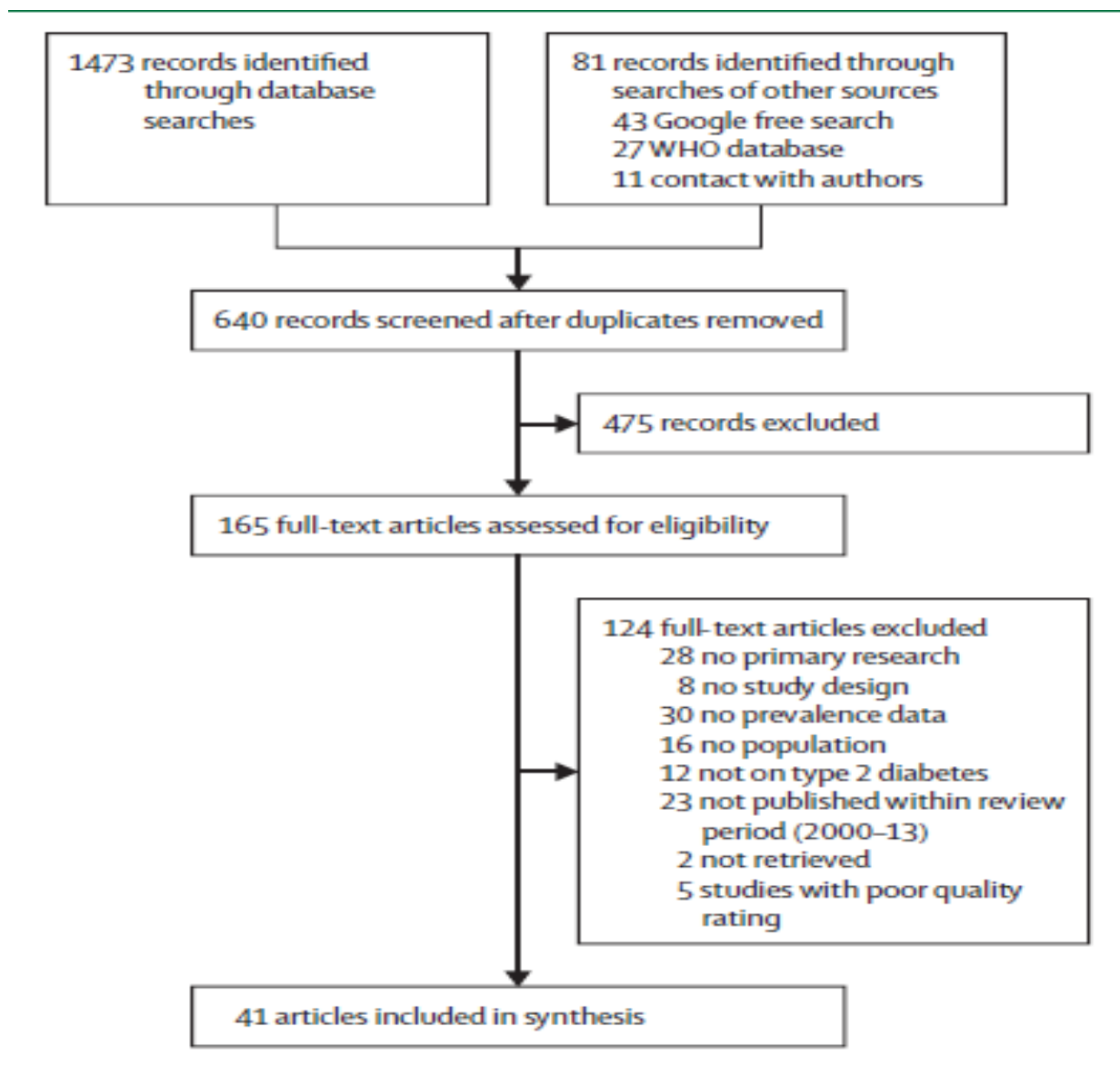


Figure 4-1 Selection of articles for inclusion in the systematic review

4.3.2. Assessment of risk bias in included studies

We evaluated the methodological quality of included studies in terms of internal validity, external validity, response rate, and generalisability of study results. We used the ten-item rating system developed by Hoy and colleagues (14) and modified by Werfalli and colleagues (15) (Appendix 5) to assess sampling, the sampling frame and size, outcome measurement, outcome assessment, response rate, and statistical reporting. (14) Each item was assigned a score of 1 (yes) or 0 (no), and scores were summed across items to generate an overall quality score that ranged from 0 to 10. Each study was rated as having a low, moderate, or high risk of bias dependent on the number of questions answered as “yes” (low risk): studies at low risk of bias had scores higher than 8, moderate a score of 6–8, and high a score of 5 or lower. (15) Risk of selection and attrition biases were assessed according to the Cochrane guidelines, in Review Manager, version 5.2. Two reviewers (MW and MEE) independently assessed study quality, with disagreements being resolved by consensus.

4.3.3. Data extraction

Two reviewers (MW and AM) independently selected studies and extracted relevant information. Disagreements were resolved by consensus or consultation with a third reviewer (NSL). Study characteristics documented included country name, year of publication, national population, region (rural or urban), age range, sex, study design, criteria for sample selection, sample size, ascertainment of diabetes status, and diagnostic criteria (Appendix 6).

4.3.4. Data synthesis and analysis

Three reviewers (MW, APK, and NSL) did the statistical analysis and data synthesis. Unadjusted prevalence estimates and Standard Errors (SEs) were recalculated for type 2 diabetes in people aged 55 years or older (number of cases/sample size) based on the information on crude numerators and denominators provided in the individual studies. To keep the effect of studies with very small or extremely large prevalence estimates on the overall estimate to a minimum, we stabilised the variance of the study-specific prevalence with the Freeman-Tukey single arcsine transformation (16) before pooling the data with the random-effects meta-analysis model. (17) Heterogeneity between studies was assessed with Cochran’s Q statistic and the I^2 statistic, (18) which estimates the percentage of total variation across studies due to true between-study differences rather than chance. I^2 values greater than 60–70% generally indicates the presence of substantial heterogeneity. We explored sources of heterogeneity by comparing diabetes prevalence between subgroups defined by several study-level characteristics. We evaluated the presence of publication bias using the Egger test of bias. (19) We did all analyses with the meta package in R (version 3.0.3) (Table 4-1).

4.4. Findings

4.4.1. Search results

The searches identified 1554 citations. After screening of titles and abstracts and removal of duplicates, 640 studies were selected for further scrutiny, of which 165 were selected for full-text review. Of these, 41 met the inclusion criteria and were included in this systematic review (Figure 4.1). (20–60)

The reasons for exclusion of 124 studies are detailed in the (appendix 12). Of the 41 studies included, two (21,35) provided prevalence estimates separately for urban and rural participants, another four (28,43,47,60) provided estimates separately for two non-overlapping age groups, and one (51) provided prevalence estimates separately for two non-overlapping age groups for urban participants and two non-overlapping age groups for rural participants. These datasets were counted separately, leading to 49 data contributions being assessed in the main analyses. Generally, the overall risk of bias was low in studies (n=31) but was moderate in 11 and high in five (Appendix 7). Twenty-five of the studies included in this systematic review were published in peer-reviewed journals (for the purpose of this Review we referred to them as non- STEPS studies), 20–43 16 were STEPS studies,44–60 and one was a thesis (23) (Tables 4-2, 4-3).

For STEPS studies published in peer-reviewed journals, we used the latest published version that included the complete dataset. Of the 54 countries of the African continent, 30 (57%), accounting for 74.3% of the total population (7 535 million of 1 136 billion), 60 were represented in this systematic review: three studies from Algeria, two from Benin, two from Cameroon, three from Democratic Republic of the Congo, two from Ethiopia, two from Libya, one from Mozambique, three from South Africa, two from Tunisia, and one from each of Angola, Botswana, Burkina Faso, Canary Islands, Egypt, Gabon, Guinea, Kenya, Mayotte, Malawi, Mauritania, Mauritius, Niger, Nigeria, Reunion, Seychelles, Sudan, Tanzania, Togo, Uganda, and Zimbabwe. The analytical sample size ranged from 467 to 10 000.

All STEPS studies used multistage cluster sampling techniques, and the response rates were 54.6–100%. The non-STEPS studies used random sampling or multistage cluster sampling techniques and had response rates of 70–99%. Twelve studies used OGTT as the method of diabetes diagnosis, and 37 studies used FPG. Forty-eight studies used WHO 1998/1999 diagnostic criteria for type 2 diabetes and one study used WHO 1985 criteria. 30 (73%) studies were done in urban and rural areas, 17 (41%) were done only in urban areas, and eight (19%) only in rural areas.

The definition of older people was 55–64 years in 21 (43%) studies, 55 years or older in six (12%) studies, 60 years or older in ten (20%) studies, 65 years or older in four (8%) studies. Some studies used more than one definition; for these studies and when the age bands were not mutually

exclusive, the age band that included the greatest age range was used in the analysis (i.e., ≥ 55 years when provided along with 55–64 years, or 60 years when provided along with ≥ 65 years old). Thus, our main analysis included 41 studies rather than the 49 data contributions. In the assessment of methodological quality, five contributions were deemed to be of poor methodological quality and were excluded from the analysis. Of the remaining 46 contributions included, 11 were deemed to be of moderate quality and 30 of high methodological quality (Appendix 8).

4.4.2. Prevalence by age, sex, region, and type of residency.

The overall prevalence of type 2 diabetes across the 49 contributions ($n=16\,086$ participants) was 13.7% (95% CI 11.3–16.3; Appendix 9) and did not differ significantly by age group ($p=0.187$) or sex ($p=0.611$; Appendix 9–11). When assessed by sex, the prevalence of diabetes was 14.3% (95% CI 11.9–17.0) overall ($n=12\,373$), 13.6% (10.7–16.9) for men ($n=5345$), and 15.0% (11.2–19.2) in women ($n=7028$). Prevalence of type 2 diabetes did not differ significantly ($p=0.181$) between sub-Saharan and north Africa (13.8%, 95% CI 13.2–14.3, 39 studies vs 16.6%, 11.7–22.3, ten studies). By contrast, the overall prevalence of diabetes was significantly higher in urban than rural populations (19.7%, 15.0–24.9, 17 studies vs 7.9%, 4.6–12.0, eight studies; $p=0.0002$).

Table 4–1 Summary and comparison statistics

Groups	Subgroups	Age groups	N studies	N participants	% (95% CI)	I ² (95% CI)	H (95% CI)	P heterogeneity	P-diff age groups	p-diff subgroups	P Egger test
Overall	None	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222		0.557
		55-64	20	6520	11.9 (8.5-15.6)	94.9 (93.2-96.1)	4.41 (3.84-5.06)	<0.0001	NA		0.303
		55+	6	1781	12.3 (6.7-19.1)	93.5 (88.6-96.3)	3.93 (2.96-5.22)	<0.0001	NA		0.297
		60+	9	4971	19.9 (12.8-27.9)	97.6 (96.6-98.3)	6.44 (5.45-7.61)	<0.0001	NA		0.117
		65+	4	1078	16.8 (6.7-30.2)	95.5 (91.3-97.6)	4.70 (3.39-6.51)	<0.0001	NA		0.523
Sex	Overall	Overall	56	11458	15.5 (12.7-18.4)	94.2 (93.1-95.1)	4.14 (3.81-4.51)	<0.0001	0.048	0.718	0.198
		Men	28	4951	14.9 (11.6-18.4)	90.5 (87.5-92.8)	3.24 (2.82-3.73)	<0.0001	0.035		0.721
		55-64	15	2734	11.5 (8.2-15.2)	87.4 (80.9-91.7)	2.82 (2.29-3.47)	<0.0001	NA		0.773
		55+	4	348	16.0 (4.8-31.8)	91.8 (82.3-96.2)	3.50 (2.37-5.15)	<0.0001	NA		0.443
		60+	5	1483	26.5 (16.6-37.8)	93.6 (87.9-96.6)	3.95 (2.88-5.41)	<0.0001	NA		0.090
	Women	65+	4	386	14.8 (3.9-30.5)	91.1 (80.4-96.0)	3.36 (2.26-4.99)	<0.0001	NA		0.476
		Overall	28	6507	16.0 (11.6-20.1)	95.9 (94.9-96.7)	4.94 (4.44-5.50)	<0.0001	0.596		0.209
		55-64	15	3002	13.6 (8.2-24.9)	95.6 (94.0-96.7)	4.75 (4.07-5.53)	<0.0001	NA		0.934
		55+	4	533	13.9 (5.6-24.9)	88.2 (72.4-95.0)	2.92 (1.90-4.47)	<0.0001	NA		0.284
		60+	5	2280	24.0 (9.5-2.3)	98.4 (97.7-99.9)	8.00 (6.53-9.81)	<0.0001	NA		0.166
		65+	4	692	18.3 (8.7-30.5)	90.6 (79.6-95.8)	3.26 (2.18-4.88)	<0.0001	NA		0.596
Residency	Overall	Overall	18	5534	17.6 (13.1-22.4)	94.7 (92.9-96.0)	4.34 (3.74-5.03)	<0.0001	0.006	0.003	0.113
		Urban	12	3503	21.0 (15.2-27.5)	94.4 (91.9-96.1)	4.22 (3.50-5.08)	<0.0001	<0.0001		0.230
		55-64	3	664	18.1 (8.9-29.5)	91.4 (77.8-96.6)	3.40 (2.12-5.46)	<0.0001	NA		0.676
		55+	2	306	12.4 (8.9-16.3)	0	0	0.638	NA		-
		60+	5	1940	23.7 (12.6-37.0)	96.5 (94.2-98.0)	5.38 (4.14-6.99)	<0.0001	NA		0.188
	Rural	65+	2	593	29.4 (25.8-33.2)	0	1	0.707	NA		-
		Overall	6	2031	10.5 (7.1-14.5)	81.0 (59.1-91.1)	2.29 (1.56-3.36)	0.0003	0.018		0.201
		55-64	1	122	5.7 (2.2-10.7)	-	-	-	-		-
		55+	1	380	6.6 (4.3-9.3)	-	-	-	-		-
		60+	3	1447	13.3 (7.2-20.7)	88.4 (67.7-95.8)	3.9 (1.76-4.88)	0.0002	NA		0.006
		65+	1	82	15.8 (8.6-24.6)	-	-	-	-		-
Region	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	0.062	0.557
	Central	Overall	5	1580	8.6 (5.4-12.3)	75.4 (39.5-90.0)	2.02 (1.29-3.16)	0.003	0.008		0.942
	Eastern	Overall	11	2863	13.8 (8.0-20.9)	96.0 (94.3-97.2)	4.97 (4.17-5.93)	<0.0001	0.0003		0.456
	Northern	Overall	10	6007	16.6 (11.7-22.3)	96.7 (95.3-97.7)	5.48 (4.60-6.53)	<0.0001	0.001		0.381

	Southern	Overall	5	1024	21.5 (9.6-36.4)	96.2 (93.5-97.8)	5.15 (3.93-6.74)	<0.0001	<0.0001		0.065
	Western	Overall	8	2876	11.3 (6.0-18.0)	96.2 (94.3-97.5)	5.14 (4.18-6.31)	<0.0001	0.313		0.966
Design data collection	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	0.042	0.557
	Non-STEPS	Overall	25	9471	16.4 (12.7-20.4)	95.9 (94.9-96.8)	4.95 (4.42-5.55)	<0.0001	<0.0001		0.273
		55-64	8	2044	13.3 (8.6-18.9)	91.3 (85.3-94.9)	3.39 (2.61-4.41)	<0.0001	NA		0.116
		55+	6	1781	12.3 (6.7-19.1)	93.5 (88.6-96.3)	3.93 (2.96-5.22)	<0.0001	NA		0.297
		60+	9	4971	19.9 (12.8-27.9)	97.6 (96.6-98.3)	6.44 (5.45-7.61)	<0.0001	NA		0.117
		65+	2	675	27.7 (24.4-31.2)	0	1	0.473	NA		NA
	STEPS	Overall	14	4879	10.4 (6.7-14.9)	95.4 (93.7-96.7)	4.67 (3.98-5.49)	<0.0001	0.564		0.320
		55-64	12	4476	11.0 (6.7-16.0)	96.0 (94.4-97.1)	4.98 (4.21-5.88)	<0.0001	NA		0.474
		55+	0	-	-	-	-	-	-		-
		60+	0	-	-	-	-	-	-		-
		65+	2	403	7.5 (0.7-19.7)	90.5	3.24	0.001	NA		NA
Type of population	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	0.937	0.557
	Subnational	Overall	23	8573	14.2 (10.8-17.8)	95.1 (93.8-96.2)	4.54 (4.00-5.15)	<0.0001	0.755		0.142
		55-64	8	2466	12.7 (7.5-19.0)	94.5 (91.2-96.5)	4.26 (3.38-5.36)	<0.0001	NA		0.872
		55+	6	1781	12.3 (6.7-19.1)	93.5 (88.6-96.3)	3.93 (2.96-5.22)	<0.0001	NA		0.297
		60+	6	3549	16.2 (10.3-23.1)	95.6 (92.7-97.4)	4.78 (3.71-6.15)	<0.0001	NA		0.054
		65+	3	777	18.2 (4.1-39.1)	96.0 (91.4-98.1)	4.98 (3.40-7.30)	<0.0001	NA		0.645
	National	Overall	16	5777	14.0 (9.5-19.1)	96.4 (95.3-97.3)	5.27 (4.59-6.06)	<0.0001	0.058		0.238
		55-64	12	4054	11.3 (7.1-16.4)	95.5 (93.6-96.8)	4.69 (3.94-5.58)	<0.0001	NA		0.245
		55+	0	-	-	-	-	-	-		-
		60+	3	1422	27.3 (14.8-41.9)	96.3 (92.1-98.2)	5.18 (3.56-7.52)	<0.0001	NA		0.813
		65+	1	301	13.0 (9.4-17.0)	NA	NA	<0.0001	-		-
Year published	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	0.484	0.557
	Below Median (2008)	Overall	17	7748	13.0 (9.1-17.4)	96.5 (95.4-97.3)	5.33 (4.66-6.09)	<0.0001	0.272		0.898
		55-64	8	3002	9.8 (5.3-15.4)	95.3 (92.7-97.0)	4.61 (3.70-5.74)	<0.0001	NA		0.172
		55+	2	720	19.9 (2.9-46.5)	98.0	6.99	<0.0001	NA		-
		60+	5	3623	18.7 (9.9-29.6)	98.2 (97.3-98.8)	7.49 (6.06-9.27)	<0.0001	NA		0.347
		65+	2	403	7.5 (0.7-19.7)	90.5	3.24	0.001	NA		-
	Above median (2008)	Overall	22	6572	14.5 (10.9-18.5)	94.7 (93.0-95.9)	4.33 (3.79-4.94)	<0.0001	<0.0001		0.412

		55-64	12	3548	15.0 (11.1-19.3)	95.3 (93.3-96.3)	4.60 (4.05-5.23)	<0.0001	NA		0.339
		55+	4	1061	8.8 (5.9-12.2)	67.2 (4.3-88.7)	1.75 (1.02-2.98)	0.027	NA		0.186
		60+	4	1348	21.5 (7.2-40.7)	97.1 (94.8-98.4)	5.85 (4.39-7.79)	<0.0001	NA		0.194
		65+	2	675	27.7 (24.4-31.2)	0	1	0.473	NA		-
Sample size	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	0.148	0.557
	Below Median (282)	Overall	19	3232	16.3 (12.1-21.0)	91.6 (88.3-93.9)	3.44 (2.92-4.06)	<0.0001	0.174		0.915
		55-64	10	2106	12.9 (8.9-17.5)	88.4 (80.7-93.0)	2.93 (2.28-3.78)	<0.0001	NA		0.146
		55+	3	501	18.3 (7.0-33.2)	93.2 (83.5-97.2)	3.84 (2.46-5.98)	<0.0001	NA		0.685
		60+	4	446	26.6 (14.9-40.3)	89.5 (75.9-95.4)	3.08 (2.04-4.67)	0.056	NA		0.356
		65+	2	179	14.0 (0.0-50.5)	96.6	5.45	<0.0001	NA		-
	Above median (282)	Overall	20	11118	12.2 (8.8-16.1)	97.1 (96.4-97.7)	5.89 (5.25-6.61)	<0.0001	0.054		0.661
		55-64	10	4414	10.9 (6.2-16.7)	96.9 (95.6-97.8)	5.66 (4.77-6.71)	<0.0001	NA		0.172
		55+	3	1280	7.7 (5.8-9.9)	48.0 (0.0-84.8)	1.39 (1.00-2.57)	0.146	NA		0.037
		60+	5	4525	15.5 (8.0-24.7)	98.4 (97.6-98.9)	7.91 (6.44-9.72)	<0.0001	NA		0.017
		65+	2	899	19.8 (7.7-35.6)	96.2	5.14	<0.0001	NA		-
Diagnostic methods	Overall	Overall	39	14350	14.1 (11.4-17.1)	95.8 (94.9-96.5)	4.87 (4.44-5.34)	<0.0001	0.222	<0.0001	0.557
	FPG	Overall	27	10935	10.5 (8.3-12.9)	93.2 (91.1-94.7)	3.82 (3.36-4.35)	<0.0001	0.625		0.711
		55-64	16	5215	10.2 (6.8-14.1)	94.7 (92.7-96.1)	4.34 (3.71-5.08)	<0.0001	NA		0.300
		55+	4	1206	9.6 (7.0-12.6)	57.8 (0-86.0)	1.54 (1.0-2.67)	0.0684	NA		0.500
		60+	5	4111	13.0 (8.6-18.1)	94.7 (90.5-97.1)	4.36 (3.24-5.87)	<0.0001	NA		0.365
		65+	2	403	7.5 (0.7-19.7)	90.5	3.24	0.0012	NA		NA
	OGTT	Overall	12	3415	24.0 (17.7-30.7)	94.9 (92.6-96.4)	4.41 (3.68-5.29)	<0.0001	0.116		0.947
		55-64	4	1305	19.7 (14.2-25.8)	84.6 (61.7-93.8)	2.55 (1.62-4.03)	0.0002	NA		0.742
		55+	2	575	17.7 (0.7-49.2)	98.4	7.94	<0.0001	NA		NA
		60+	4	860	29.7 (18.3-42.5)	92.0 (82.8-96.3)	3.54 (2.41-5.21)	<0.0001	NA		0.432
		65+	2	675	27.7 (24.4-31.2)	0	0	0.473	NA		NA
Age	Overall	Overall	42	14704	13.8 (11.2-16.6)	95.5 (94.6-96.2)	4.70 (4.29-5.14)	<0.0001	0.213	0.213	0.776
	55-64	Overall	22	6757	11.5 (8.4-15.0)	94.4 (92.6-95.7)	4.22 (3.68-4.82)	<0.0001	NA		0.245
	55+	Overall	6	1781	12.3 (6.7-19.1)	93.5 (88.6-96.3)	3.93 (2.96-5.22)	<0.0001	NA		0.297
	60+	Overall	10	5088	19.0 (12.5-26.5)	97.3 (96.2-98.0)	6.08 (5.16-7.16)	<0.0001	NA		0.144
	65+	Overall	4	1078	16.8 (6.7-30.2)	95.5 (91.3-97.6)	4.70 (3.39-6.51)	<0.0001	NA		0.523

Table 4–2 Prevalence of type 2 diabetes in older populations assessed in studies not using the WHO STEPwise approach to surveillance

Country	Author	Sampling			Age	Prevalence (%) (95%CI)									Diagnosis		IFG and/ or IGT prevalence % (95% CI)
		Size	Strategy	Response Rate (%)		Urban			Rural			Urban +Rural			Method	Criteria	
						M	F	T	M	F	T	M	F	T			
Algeria	Malek 2001	1457	Random sampling	90	55-64 60+	-	-	-	-	-	-	-	-	11.2 12.0	OGTT	WHO 1998	17.43 for IGT
	Zaoui 2007	7656	Random sampling	NR	60+	17.4	5.7	10.3	10.2	7.2	8.3	14.2	6.4	10.5	FPG	WHO 1985	NR
Angola	Evaristo Neto 2012	709	Random	71	60 - 69	-	-	14.6	-	-	-	-	-	-	FPG OGTT	WHO 1998	20.8 for IGT
Cameroon	Nchanchou 2008 (Thesis)	1279	Multistage sampling	>95	55+	15.2	10.8	13.1	-	-	-	-	-	-	FPG	WHO 1998	6.8 for IFG
Canary Islands	Boronat 2005	1193	Random sampling	86.3	55+	-	-	-	-	-	-	39.6	26.3	32.8	FPG OGTT	WHO 1998	5.1 for IFG 10.6 for IGT
DRC	On’Kin 2008	9770	Multistage sampling	90.3	55 -64 65 - 98	- -	- -	- -	- -	- -	- -	37.7 36.1	44.5 30.6	41.4 33.4	FPG OGTT	WHO 1998	15 for IGT 15.5 for IGT
	Katchunga 2012	711	Multistage sampling	98.6	60+	-	-	-	-	-	-	-	-	8.3	FPG	WHO 1998	NR
Ethiopia	Muluneh 2012	5500	Random sampling	81.3%	55+	-	-	-	-	-	-	-	-	6.7	FPG	WHO 1998	NR
Guinea	Balde 2007	2000	Multistage	77	55–64	-	-	-	-	-	-	-	-	7.8	FPG	WHO	NR

			sampling		65+	-	-	-	-	-	-	-	-	6.1		1998	
Kenya	Ayah 2013	2061	Cluster sampling	99	55+ 55-64	7.6 2.0	16.7 17.9	11.1 7.7	- -	- -	- -	- -	- -	- -	FPG	WHO 1998	NR
LaReUnion	Favier 2005	3600	Random sampling	80.6	60+	-	-	-	-	-	-	34.6	40.0	37.7	FPG OGTT	WHO 1998	NR
Libya	Kadiki 2001	1002	Multistage sampling	86.6	60+	-	-	34.9	-	-	28.3	30.2	17.8	24.5	OGTT	WHO 1998	7.6 for IGT
Mayotte	Solet 2011	1268	Random sampling	70	60+	25.9	-	-	-	-	-	-	-	-	FPG	WHO 1998	NR
Mozambique	Silva Matos 2011	2343	Random sampling	NR	55-64	-	-	8.7	-	-	5.7	-	-	-	FPG	WHO 1998	1.1 for IFG (U) 5.1 for IFG (R)
Nigeria	Ekpenyong 2012	2780	Random sampling	97.3	55-64	-	-	-	-	-	-	14.3	34.8	21.5	FPG OGTT	WHO 1998	NR
Seychelles	Faeh 2007	1255	Random sampling	80.2	55-64	22.0	26.5	24.5	-	-	-	-	-	-	FPG OGTT	WHO 1998	23.25 for IFG 17.3 for IGT
South Africa	Erasmus 2012	642	Random sampling	87.6	60+	11.8	7.7	43.6	-	-	-	-	-	-	FPG OGTT	WHO 1998	1.8 for IFG 16.4 for IGT
	Peer 2012	1099	Random sampling	86	55-64 65-74	17.3 42.9	26.9 34.7	22.7 31.2	- -	- -	- -	- -	- -	- -	OGTT	WHO 1998	0.8 for IFG 16.9 for IGT 1.1 for IFG 19.9 for IGT
	Motala 2008	1300	Cluster sampling	78.9	55+ 55-64	- -	- -	- -	6.3 13.7	7.7 7.6	6.6 8.8	- -	- -	- -	FPG OGTT	WHO 1998	1.3 for IFG 8.8 for IGT 1.8 for IFG 12.7 for IGT
Tunisia	Bouguerra 2007	2729	multistage stratified	85.1	60+	19.8	27.4	24.3	10.6	12.4	11.5	15.8	21.9	19.2	FPG	WHO 1998	NR
	Hammami 2012	598	multistage cluster sampling	96.3	65+	32.0	28.0	29.3	15.2	16.3	15.9	29.2	26.5	27.4	FPG OGTT	WHO 1998	NR

Uganda	Mayega 2013	1497	Random sampling	90.4%	55-60	-	-	-	-	-	-	-	-	9.2	FPG	WHO 1998	8.6 for IFG
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Table 4–3 Prevalence of type 2 diabetes in older populations assessed in studies using the WHO STEPwise approach to surveillance

Country	Survey year	Sampling			Age Range	Prevalence (%) (95%CI)			Diagnosis		IFG and/ or IGT prevalence % (95% CI)
		Size	Stratgy	Rate of response %		Urban + Rural			Method	Criteria	
						M	F	All			
Algeria	2003 (S)	4,097	Multi-stage cluster sampling	3,820 93.2	55-64	6.4	5.1	5.6	FPG	WHO 1998	NR
Benin	2008 (N)	6,842	Multi-stage cluster sampling	6,511 95.2	55-64	15.5	17.7	15.9	FPG	WHO 1998	NR
Botswana	2007 (N)	4,003	Multi-stage cluster sampling	2,820 70.4	55-64	4.2	8.2	12.3	FPG	WHO 1998	NR
DRC	2005 (S)	1,943	Multi-stage cluster sampling	1,123 (57.8)	55-64 65+	5.2 2.1	6.2 3.7	5.7 2.9	FPG	WHO 1998	NR
Egypt	2006 (N)	10,000	Multi-stage cluster sampling	9730 97.3	55-64	17.2	28.7	22.6	FPG	WHO 1998	NR
Gabon	2009 (N)	2800	Multi-stage cluster sampling	2708 96.7	55-64	-	-	22.2	FPG	WHO 1998	NR
Libya	2009 (N)	3625	Multi-stage cluster sampling	2646 73.0	55-64	25.6	33.4	29.0	FPG	WHO 1998	NR
Malawi	2010 (N)	5206	Multi-stage cluster sampling	2842 54.6	55-64	0.0	1.2	6.6	FPG	WHO 1998	NR
Mauritania	2006 (N)	2600	Multi-stage cluster sampling	2500 96.1	55-64 60-69 70+	3.7 36.2 36.6	3.2 38.7 42.9	3.4 37.6 39.7	FPG	WHO 1998	NR
Mauritius	2004 (N)	4500	Multi-stage cluster sampling	4200 93.3	60-69 70+	36.2 36.6	38.7 42.9	37.6 39.7	FPG OGTT	WHO 1998	16.2 for IGT 18.4 for IGT
Niger	2008 (N)	3060	Multi-stage cluster sampling	90.8	55-64	4.4	0.8	3.2	FPG	WHO 1998	NR
Sudan	2006 (S)	1573	Multi-stage cluster sampling	921 58.5	55-64	19.9	16.2	17.9	FPG	WHO 1998	NR
Togo	2010 (N)	4800	Multi-stage cluster sampling	4370 91.0	55-64	11.0	3.6	7.5	FPG	WHO 1998	NR
Zimbabwe	2005 (N)	3000	Multi-stage cluster sampling	3081 102	55-64 65+	15.7 18.5	14.0 15	14.4 16.8	FPG	WHO 1998	NR
*Data extracted from peer reviewed published and unpulished studies other than WHOSTEPS studies. FPG, fasting plasma glucose; OGTT, oral glucose tolerance test; IFG, impaired fasting glucose (fasting plasma glucose: 5.6 to 6.9 mmol/l); IGT, impaired glucose tolerance (2-h post challenge glucose: 7.8–11.0 mmol/l); NR, not reported; M, Male ; F, Female;WHO 1998, the World Health Organization definition of diabetes in 1998 (FPG 7.0 mmol/l and/or 2-h PG 11.1 mmol/l).											

4.4.3. Prevalence by method of data collection (STEPS vs non-STEPS).

The prevalence of type 2 diabetes was significantly lower in STEPS studies ($p=0.003$) than in non-STEPS studies (9.6%, 95% CI 6.6–13.0, 20 contributions vs 17.1%, 13.6–20.9, 29 contributions; Figures 4-2,4-3). There was a significant difference across age groups in the non-STEPS studies ($p<0.0001$), but not across the STEPS surveys ($p=0.550$, appendix 15). No difference in prevalence was seen between studies larger and smaller than the median sample size ($p=0.592$), although there was a significant age differential among studies above the median sample size ($p=0.008$). Heterogeneity remained significant ($p<0.0001$) within the STEPS and non-STEPS age groups (Figures 4-2, 4-3).

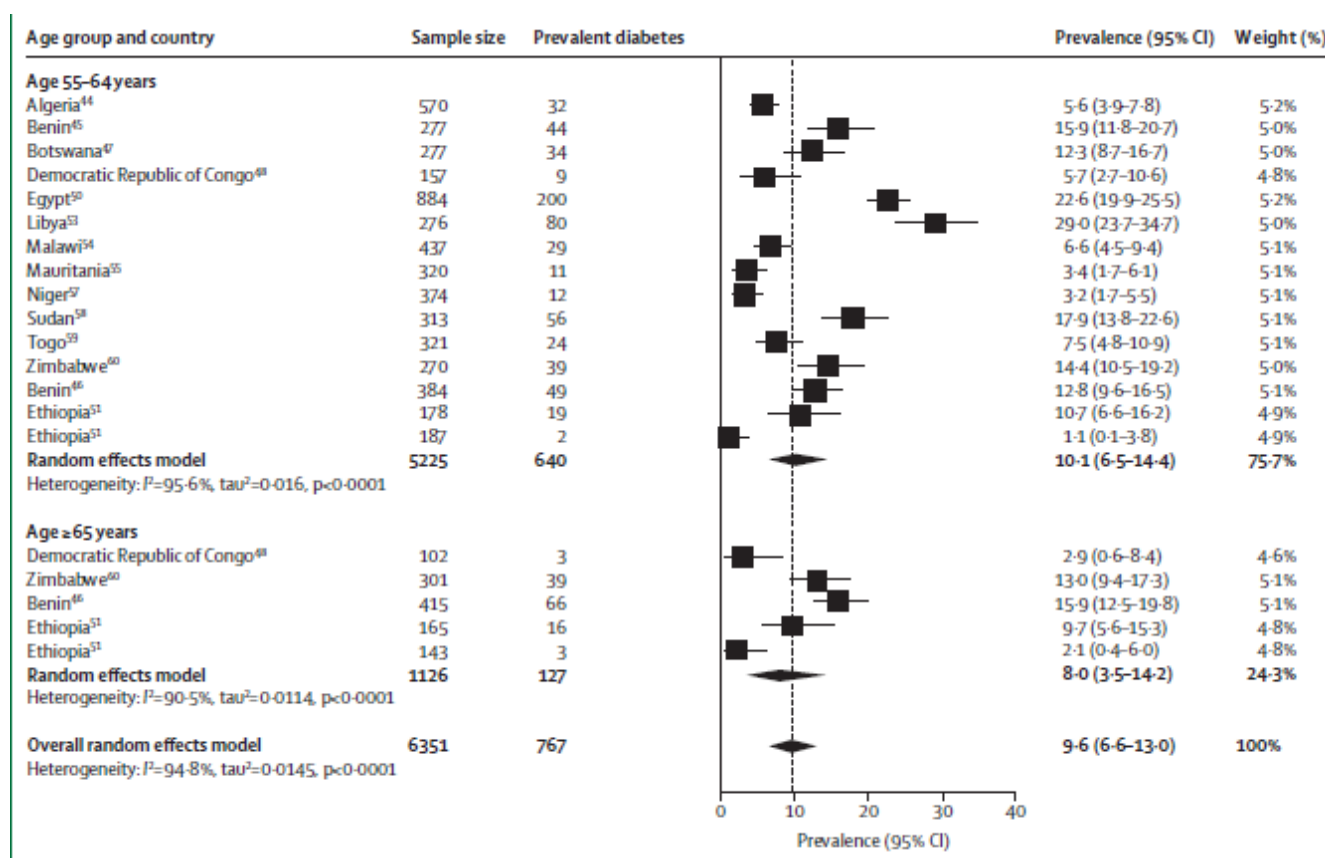


Figure 4–2 Meta-analysis results for prevalence of type 2 diabetes in studies using the WHO STEPwise approach to surveillance

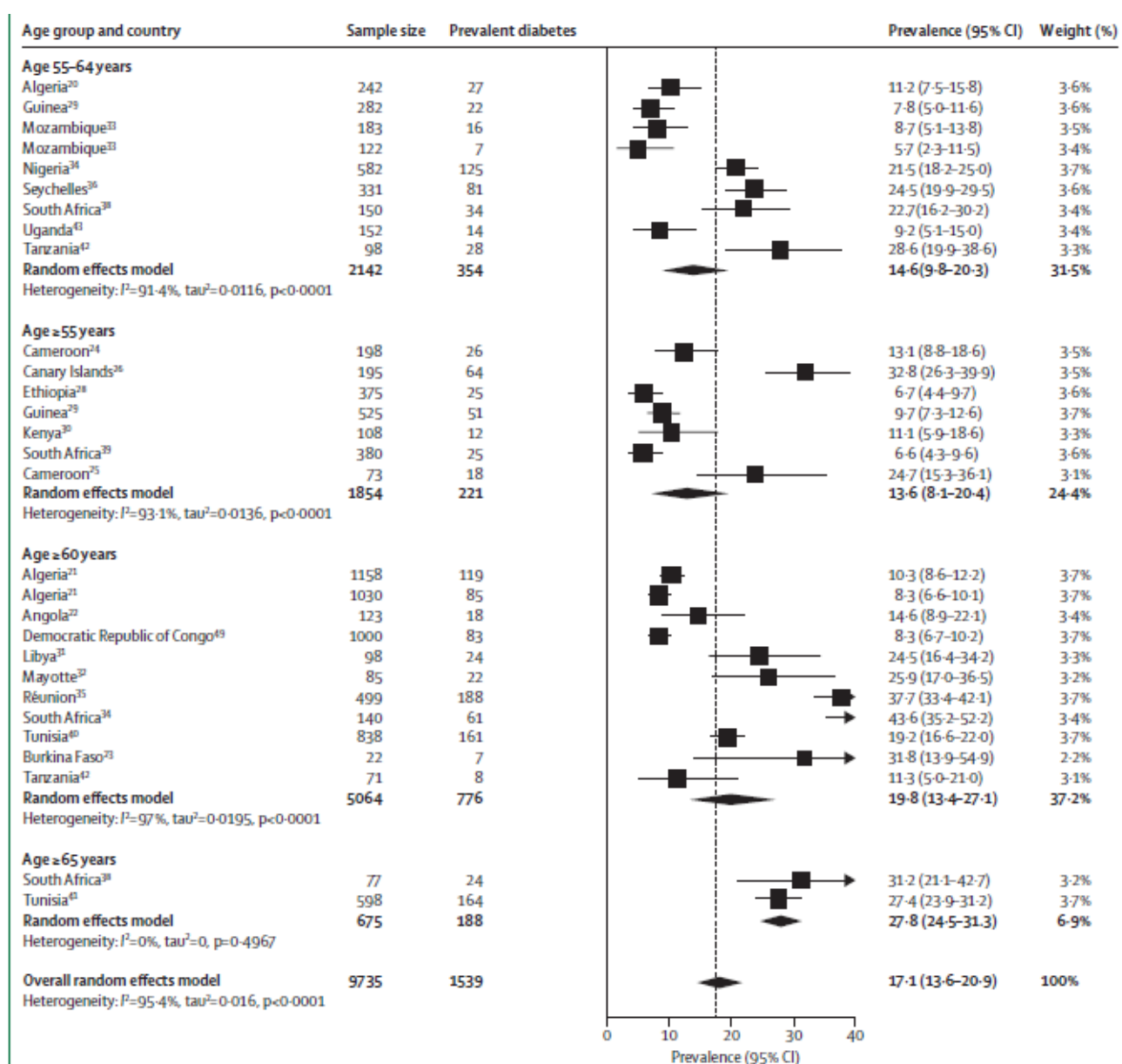


Figure 4–3 Meta-analysis results for prevalence of type 2 diabetes in studies not using the WHO STEPwise approach to surveillance.

4.4.4. Prevalence by diagnostic method (FPG vs OGTT)

When diagnosed with FPG the prevalence of type 2 diabetes was 10.9% (95% CI 8.9–13.0; 37 contributions) and when diagnosed with OGTT was 23 · 9% (17.7–30.7; 12 contributions, p-value for difference <0 · 0001; Figures 4-4, 4-5). When studies that used the same diagnostic method were compared, prevalence did not differ between age groups (p=0.410 for FPG and p=0.117 for OGTT). When the prevalence of diabetes was compared across the different regions (eastern, western, central, northern, and southern) after stratification by the diagnostic method, prevalence did not differ (p=0.139 for OGTT and p=0.070 for FPG), in line with the main analysis

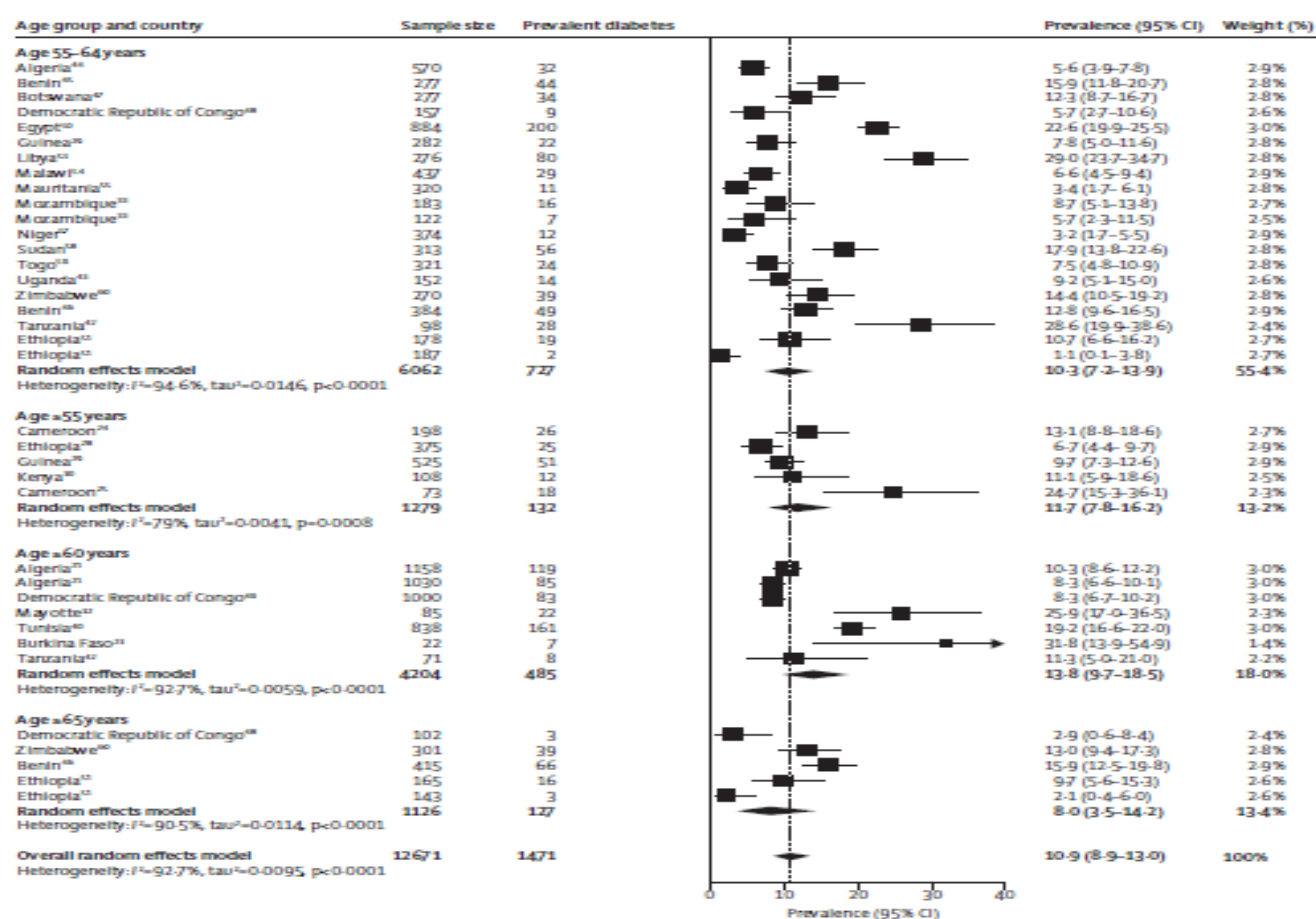


Figure 4–4. Meta-analysis results for prevalence of type 2 diabetes in studies in which diabetes diagnosis was based on fasting plasma glucose.

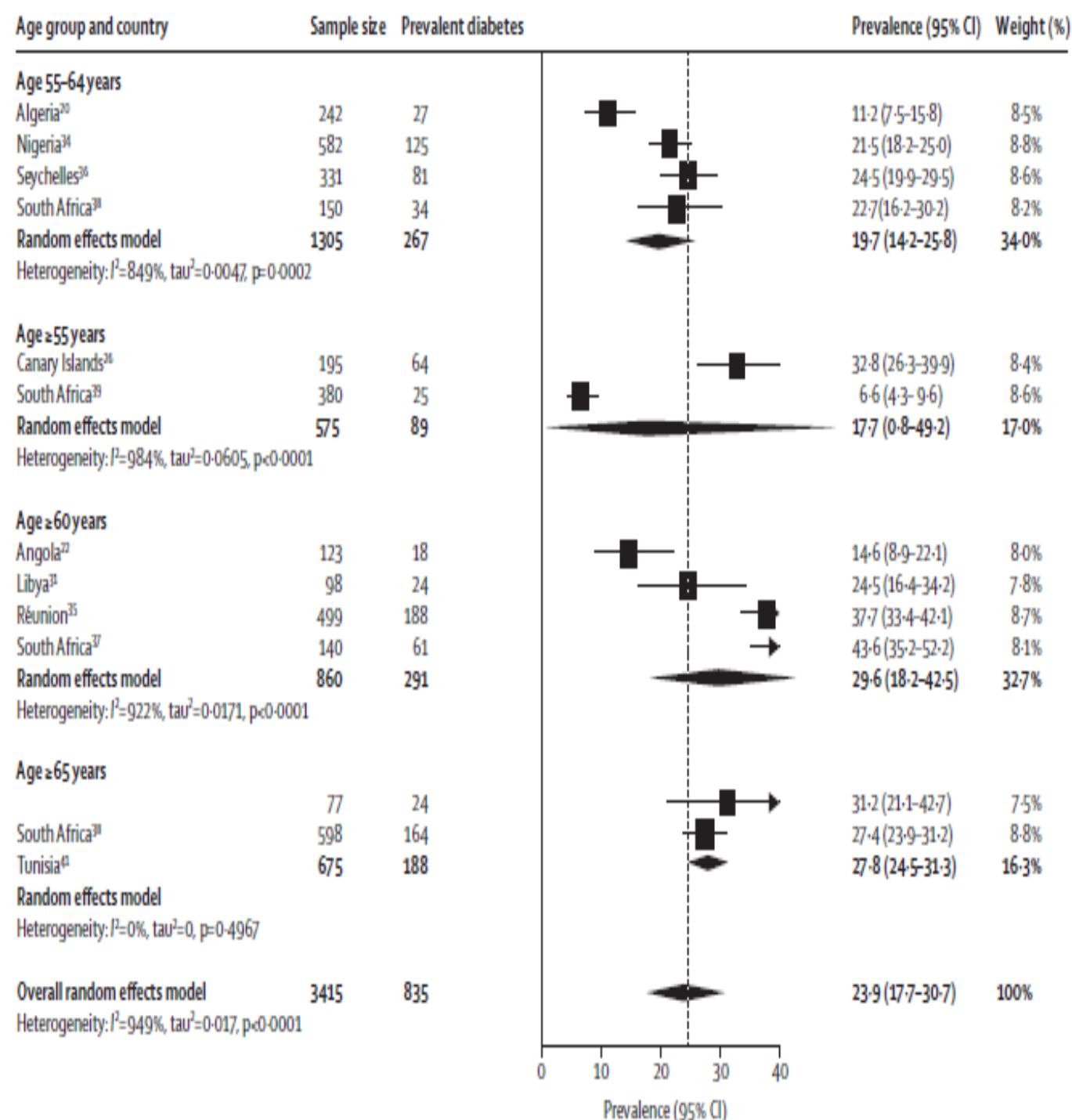


Figure 4--5 Meta-analysis results for prevalence of type 2 diabetes in studies in which diabetes diagnosis was based on using the oral glucose tolerance test.

4.4.5. Investigation of the sources of heterogeneity

Substantial heterogeneity was seen across the contributing studies overall, within subgroups for sex, age, residence, and median sample size, across diagnostic methods, and across data collection methods (all $p < 0.0001$ for heterogeneity). We found no evidence of publication bias (Egger score) overall and in most age groups (Table 4–1).

4.5. Discussion

Our systematic review showed that type 2 diabetes is not rare in people aged 55 years and older across Africa. The estimated prevalence of diabetes was two times higher in studies that used OGTT than in those that used FPG to diagnose diabetes and was nearly twice as high in urban than in rural settings. The two main methods used to survey diabetes prevalence were also associated with different results: non-STEPs studies showed a prevalence 1.6 times higher than STEPS studies. Prevalence did not, however, differ by sex, sample size, year of publication, region, or population coverage. When stratified by age group, the prevalence of diabetes

varied within some major subgroups, but not all. The prevalence and number of people affected by diabetes varies worldwide. The latest IDF Atlas reports that the highest number of people with diabetes between ages 20 and 79 years is in the western Pacific Region, where 138 million people are affected, although prevalence is 8.6%, which is close to the global estimate. The North American and Caribbean region has the highest prevalence at 11%, with an estimated 37 million people affected, followed by the Middle East and North African region, where prevalence is 9.2% and 35 million people are affected. In Europe, the prevalence and number affected are estimated to be 8.5% and 56 million people, in South and Central America the values are 8.1% and 25 million people, and in Africa 4.9% and 22 million people, which are the lowest values. (61) According to the Atlas, the three African countries with the highest prevalence are Gabon (10.7%), Reunion (15.4%), and Seychelles (12.1%). (62) The 2014 Atlas did not report the data stratified by age group or diagnostic method. (61)

The overall estimated prevalence in this review of African studies fell within that for people aged 60–79 years in 13 European countries in the DECODE study (63) and those aged 60–69 years in the Chinese and Japanese cohorts in the DECODA study. (64) The prevalence was, however, lower than that in people older than 65 years from the USA NHANES survey in 2006, (65) and in people aged 60–69 years in the Indian cohorts of the DECODA study (31.0% in the former, and 41.4% and 34.6% in men and women in the latter).

The two times higher overall estimated prevalence of diabetes we found in African studies when the diagnosis was made with OGTT than with FPG criteria is in line with findings in previous reports. Many studies have reported that FPG and two h glucose concentrations from OGTT are not consistent in detecting diabetes in the same people. For example, in the DECODE study, (63) of the 1517 people with newly diagnosed diabetes, 40% met only the FPG criterion, 31% met only the 2 h plasma glucose criterion, and 28% met both. Therefore, use of only FPG would not have identified around 30% of people with diabetes. Those investigators, therefore, concluded that diabetes would be underestimated in the older population in Europe if diagnoses were based on FPG. In the Rancho Bernardo study in the USA, (66) new diagnoses of diabetes were made more frequently with OGTT than with FPG; 70% of women and 48% of men aged 50–89 years were diagnosed by 2 h plasma glucose alone. (66) The researchers noted that diabetes defined by OGTT alone is common in older adults since the results with OGTT increase with increasing age, which more than doubles the risk of fatal cardiovascular disease and of heart disease in older women. The use of FPG alone for screening or diagnosis of diabetes might not identify older adults in these risk groups and, therefore, they should be reassessed if a diagnosis was made with this method. These differences have important implications for Africa, where STEPS surveys were based on protocols that recommended the use of FPG as a core component of biochemical measurement, as such studies are becoming a growing source of information about diabetes prevalence data. Our data and those of previous studies suggest that if the use of FPG alone were followed in practice, half of the diabetes burden in the people older than 55 years would be missed. Comparison of mortality in people with a diagnosis of diabetes based on FPG or OGTT has consistently shown worse clinical outcomes with the latter. For example, in the DECODE study, (63) the hazard ratios for death in people with diabetes diagnosed by FPG were 1.6 (95% CI 1.4–1.8) for all-cause mortality, 1.6 (1.3–1.9) for cardiovascular mortality, and 1.6 (1.4–1.9) for non-cardiovascular mortality. For OGTT, the equivalent hazard ratios were 2.0 (1.7–2.3), 1.9 (1.5–2.4), and 2.1 (1.7–2.5), respectively. (63)

On the basis of findings from three population-based longitudinal studies in Mauritius, Fiji, and Nauru, Shaw and colleagues (67) reported a 2.7-time increase in risk for all-cause mortality in men and 2.0 times in women with newly diagnosed diabetes based on OGTT, compared with people with normal glucose tolerance. By contrast, people with diagnoses based on FPG had no increased risk. Similar findings have been reported in the Hoorn study. (68) Thus, OGTT should be used rather than FPG to diagnose new cases of diabetes. The higher prevalence of diabetes in urban than in rural settings is in agreement with findings from studies done in other countries (69–72). Urbanisation in Africa, as elsewhere, is associated with notable changes in lifestyle, including decreased physical activity. In rural African communities, full-time labour-intensive subsistence farming is a common means of

livelihood and transport is active i.e., walking or cycling—particularly in individuals with low socioeconomic status. In urban areas, although there is still little leisure time, active transport and the levels of occupation-related and total physical activity are substantially reduced compared with the rural setting. Additionally, living in rural and traditional environments is associated with consuming diets incorporating more fruit and vegetables than in urban settings (62,73–76). By contrast, diets in urban areas are associated with increased intake of animal fat and refined carbohydrates, including fast foods and sugar-sweetened foods and drinks, since, notwithstanding the widespread poverty in urban areas, access to these types of food is much easier than in rural areas. (77,78)

Food insecurity, a risk factor for obesity, is an important issue for the urban poor in Africa. Although studies have revealed a strong positive relationship between obesity and high socioeconomic status, the obesity burden might be shifting to sections of the poor urban population, where people might have little knowledge and financial resources to adopt healthier lifestyles. (78–84) The implications of the rural-urban gradient in diabetes prevalence are profound for Africa, where countries are currently facing one of the most rapid rates of increased urbanisation worldwide. At present, the average annual rate of urbanisation is 3.2%, and it is predicted that 47.7% of the African population will be living in urbanised areas within 15 years, which equates to an estimated 744 million people living in cities by 2030. Therefore, a striking increase in the prevalence and number of adults with type 2 diabetes and associated risk factors is likely. (85)

Our findings have important policy implications for Africa. Although the attention of policymakers is finally extending beyond HIV/AIDs, tuberculosis, and malaria to non-communicable diseases, the enormity of this latter epidemic, including diabetes, is not fully appreciated. Increased survival in people taking antiretroviral therapy and increased longevity in those who are HIV negative, together with urbanisation, will place an ever-increasing burden on the already stretched health-care services in Africa unless aggressive preventive strategies are put in place. If monitoring of secular trends in the incidence and prevalence of diabetes associated with the epidemiological transition across all African countries is to be successful, use of standardised methods will be necessary. African countries that have done STEPS surveys must be encouraged to move towards having a regular cycle of risk factor surveillance reflected in national reporting of non-communicable diseases, and especially plans of action for diabetes. The questionnaire items and measures used in STEPS and the indicators reported from STEPS surveys need to be periodically reviewed to adapt to the latest scientific standards and policy needs in different countries. (86,87)

The issue of which test to use for diabetes prevalence studies (OGTT, FPG, or HbA1c) in Africa is complex, because decisions have to take into account cost, convenience, and reliability. Measurement of trends over time will be made difficult if diagnostic criteria change. There is little doubt that HbA1c would be the simplest indicator for diabetes because it avoids the need for fasting and measurement of glucose concentrations at 2 h for an OGTT. HbA1c also has less within-individual variation and better predicts microvascular and macrovascular complications than FPG and OGTT. The cut-off s for diabetes with HbA1c, however, have not been established for African populations, which is important to address. The use of HbA1c in epidemiological studies will only be viable once reliable, cost-effective, point-of-care equipment has been developed. Furthermore, if HbA1c were to become the standard test for diabetes prevalence studies, it would only be possible to assess trends once new baseline estimates with this method had been established. Irrespective of the diagnostic criteria or test used, future studies must assess the prevalence of type 2 diabetes according to uniform case definition and diagnostic methods and provide standardised prevalence values for older people across Africa to enable comparisons across the continent.

African countries also need encouragement to move from the subnational implementation of STEPS surveys to capturing national prevalence data. Increased collaboration between African governments and WHO is also needed to make the data collected from STEPS widely available so that they can be used to strengthen strategies for prevention and management of non-communicable diseases, including type 2 diabetes. (87) Indeed, there is a clear obligation to invest in surveillance, diabetes prevention, and creation of affordable, innovative models of health-care access and systems to halt the growing burden of diabetes in Africa. In the meantime, primary prevention should focus on targets suggested by evidence, such as improving access to health care, health education, and countering risk factors for vascular disease, including, hypertension and obesity in middle age, smoking, and physical inactivity.

Our systematic review has several strengths. We used a comprehensive review protocol (15) and made extensive effort to identify all the available evidence without language restrictions. We reported this systematic review according to PRISMA guidelines. We applied an African search filter, searched multiple electronic databases, and used a rigorous approach to select studies for inclusion. Another important strength is that we controlled for the effect of multiple-publication bias in the analysis of the results by avoiding inclusion of duplicate publications that might have skewed the interpretation of the prevalence estimates. Similarly, we appraised the methodological quality of individual studies with standard quality assessment tools for prevalence studies. Use of an arcsine

transformation to stabilise the variance of primary studies before pooling limited the effects of studies with small and large prevalence values on the pooled estimates overall and across subgroups.

Our findings should be interpreted in the context of some limitations. First, data on the prevalence of diabetes in people aged 55 years and older in Africa over the past 15 years are scarce and, therefore, describing trends of diabetes prevalence over time was not possible. Second, our ability to assess the quality of studies that we identified was limited by the methodological information provided, some of which was incomplete. Differing study sample sizes might partly explain variability in diabetes estimates. Third, we found notable heterogeneity in prevalence measures of type 2 diabetes, which was incompletely explained by subgroup analyses. Despite substantial differences, we could pool data to provide useful estimates. Fourth, most primary studies lacked data on key covariates that could have been used in meta regression analyses to explore further and control for the sources of variations in prevalence between studies.

Our cut-off of age 55 years for the older population could be questioned. In reality, the definition of older is somewhat arbitrary. For example, the United Nations uses a cutoff of 60 years, whereas, for research purposes, the cut-off for older populations is frequently 60 or 65 years. (88) Traditional African definitions of a so-called older or elderly person correlate with the chronological ages of 50–65 years, dependent on the setting, region, and country. (89) Age 50 years was used as the lower cut-off for the Minimum Data Set Project on Ageing in sub-Saharan Africa (90) because this threshold was thought to be more realistic than age 60 years for African populations. Furthermore, a collection of data from the age of 50 years might show emerging trends that would be of assistance to policymakers and for health-care planning. (90)

Many parts of Africa have only recently entered demographic transition, which accounts for the evidence that older people represent just over 5% of the African population in 2014. (91,92) Yet, the ageing population in Africa is growing at a much faster pace than in any other continent and has been accompanied by an increase in the median population age and changes in the dependency ratio. Thus, the proportion of the population composed of children has decreased, and that of people aged 60 years and older has increased. By 2050, the older population in Africa is projected to more than triple to reach 205 million. Furthermore, the widespread access to antiretroviral therapy over the past 4–5 years in sub-Saharan Africa has already had a substantial effect on life expectancy and will contribute to the growing number of older people in Africa; thus, the number of people at risk of type 2 diabetes and cardiovascular disease will also increase. Indeed, the projected worldwide median life expectancy in people living with HIV is 75 years, which is only seven years less than that for the general population. (93)

We cannot give an accurate assessment of the contribution that diabetes in the older population makes to the total adult burden of diabetes in Africa but, on the basis of this review and population data, we estimate that 9 million Africans aged 55 years and older are living with diabetes in 2015. Accordingly, a concerted effort from multiple sectors will be crucial to ensuring improved health-care delivery for people with diabetes to reduce the unacceptably high levels of morbidity and mortality in the African region.

4.6. Conclusion

The substantial burden of diabetes in the older population is an important health issue for African countries. Uniform diagnostic methods are needed to assess trends in diabetes prevalence within and between countries. Such uniformity will better enable diabetes prevention strategies to be put in place and collaborative initiatives to be developed between key international and national diabetes and geriatric organisations that can do further research and, ultimately, improve diabetes care for older people in Africa and worldwide.

Contributors

All authors conceived the study and were responsible for designing the protocol. MW, MEE, APK, and NSL designed the study. MW did the literature search and, together with AM, selected the studies, extracted the relevant information. All authors synthesised the data. MW wrote the first draft of the paper. MEE, APK, and NSL provided critical guidance on the analysis and overall direction of the study. All authors critically revised successive drafts of the paper and approved the final version.

Declaration of interests

We declare no competing interests.

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Chapter 5

Study 2: Diabetes in South African older adults: prevalence and impact on quality of life and functional disability – as assessed using SAGE Wave 1 data.

Role of the candidate

I, Professors Naomi Levitt and Sebastiana Kalula (NSL, SK) conceived the study. I collated and cleaned the data, ensuring it was accurate, and prepared the datasets for analysis. I provided critical inputs to the analysis and interpretation of the data and results. I wrote the initial manuscript for this study.

Role of the Co-authors

Dr Reshma Kassanjee analysed the data, all coauthors, NSL, SK and Dr Reshma Kassanjee provided critical inputs to the analysis and interpretation of the data and results. All authors read and approved the final manuscript.

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5.1. Abstract

Background

Diabetes is a chronic disease with severe late complications. It is known to impact the quality of life and cause disability, which may affect an individual's capacity to manage and maintain longer-term health and well-being.

Objectives

To examine the prevalence of self-reported diabetes, and the association between diabetes and each of health-related quality of life and disability amongst South Africa's older adults. To study both the direct relationship between diabetes and these two measures, as well as moderation effects, i.e. whether associations between other factors and these measures of well-being differed between individuals with diabetes and those without.

Methods

Secondary analyses of data on participants aged 50 years and older from the Study on global AGEing and adult health (SAGE) in South Africa Wave 1 (2007–2008) were conducted. Prevalence of self-reported diabetes was assessed. Multivariable regressions describe the relationships between each of quality of life (WHOQoL) and disability (WHODAS), and diabetes, while controlling for selected socio-demographic characteristics, health risk behaviours and co-morbid conditions. In the regression models, we also investigated whether diabetes moderates the relationships between these additional factors and WHOQoL/ WHODAS.

Results

Self-reported diabetes prevalence was 9.2% (95% CI: 7.8,10.9) and increased with age. Having diabetes was associated with poorer WHOQoL scores (additive effect: -4.2; 95% CI: -9.2,0.9; p-value <0.001) and greater disability (multiplicative effect: 2.1; 95% CI: 1.5,2.9; p-value <0.001). Lower quality of life and greater disability were both related to not being in a relationship, lower education, less wealth, lower physical activity and a larger number of chronic conditions. Conclusions: Diabetes is associated with lower quality of life and greater disability amongst older South Africans. Attention needs to be given to enhancing the capacity of health systems to meet the changing needs of ageing populations with diabetes in SA as well as facilitating social support networks in communities.

5.2. Background

Populations are ageing worldwide, and the pace of the demographic transition is fastest in developing countries, including those in Africa. (1) The number of people aged 60 years and older in sub-Saharan Africa is projected to be double that in Northern Europe by 2050, and to rise faster than any other region, increasing almost fourfold: from 46 million in 2015 to 157 million by 2050, (2) South Africa (SA) has one of the largest ageing populations in Africa with more than 1 in 6 individuals aged 50 years and older. Almost 8% of the current population is aged 60 years and older equating to approximately 4.2 million people and is projected to rise. The number of those aged 60 years and older is projected to rise to 10.1 million (15%) by 2050 (3). Concomitant with people living longer and an expanding older section of the population is an increase in chronic morbidity. Type 2 diabetes mellitus is typically more common in older than younger adults. Rapid urbanisation is contributing to higher disease prevalence in numerous African countries with prevalence higher in older adults than in any other age groups. (4) Untreated or inadequately managed diabetes may lead to long-term complications, including blindness, kidney disease, peripheral neuropathy and macrovascular disease, in turn leading to amputations, stroke and heart attacks. Such complications contribute significantly to mortality, morbidity and health system costs. (5) Diabetes is currently the seventh leading cause of morbidity and mortality in South Africa, due to trends in obesity, poor diet, high fasting blood glucose and low physical activity levels. (6)

Health care systems in many African countries are hard-pressed to provide adequate care to older patients with diabetes or indeed to prevent or delay the onset of the disease, in old age or earlier in the life course. Complications that arise from diabetes, particularly through inadequate management, have the potential to impact the quality of life. (6) The World Health Organization (WHO) defined the health-related quality of life (HRQoL) as 'the individual's perception of their position in life in the context of the cultural and value systems in which they lived and related to their goals, expectations, standards and concerns. (7) Provision of quality health care as a means to maintain the quality of life and well-being remains a challenge in South Africa, both in urban areas and in rural areas. The current public health care system is geared towards management of single acute diseases and not clients with complex multiple chronic conditions, such as more often seen in older than in younger patients. (8) Further complicating the situation, older clients' dissatisfaction with service delivery at public healthcare facilities has been widely documented and pertains mainly to access barriers to care. (8) Adequate management of

diabetes to prevent complications that impact the quality of life requires a supportive, accessible health care system, especially at primary care level. (7,8)

Quality of life (QoL) and disability are powerful predictors of a person's capacity to manage and maintain longer-term health and well-being. QoL is a form of evaluative well-being that refers to perceptions of the quality or goodness of one's life or one's overall life satisfaction (9). Psychological well-being and health are closely related, possibly becoming more important at older ages. (9) Age-related disability is an umbrella term that encompasses decrements in bodily function, task performance and involvement in life situations. (10) Both HRQoL and disability are health-related outcomes which reflect the overall health of an individual, including those with diabetes. (10)

The HRQoL reported by older people with chronic diseases such as diabetes may reflect its restrictive management regimen, disease sequelae, and impact of associated co-morbidities. (11) This study aimed to fill a gap in knowledge regarding the relationship between diabetes and the wellbeing and functioning of South Africans aged 50 years and older. Using data from Wave 1 of the WHO Study on global AGEing and adult health (SAGE), we investigated the prevalence of self-report diabetes and the association between diabetes and each of the WHO Quality of Life (WHOQoL) and WHO Disability Assessment Schedule (WHODAS) scores. In the analysis, we controlled for selected socio-demographic characteristics, health risk behaviours and the presence of co-morbid conditions. We also explored whether the associations between these additional factors and WHOQoL and WHODAS differed between individuals with diabetes and those without – i.e. investigated the moderation of effects by diabetes status.

5.3. Methods

5.3.1. Data source

Secondary analyses were undertaken of data from the WHO Study on global AGEing and adult health (SAGE), a longitudinal, multi-country study conducted in China, Ghana, India, Mexico, the Russian Federation and South Africa. SAGE collected individual-level data from nationally representative household samples of older adults (50 years and older) using a multistage cluster sampling design and included a smaller sample of younger adults (aged 18–49 years) for comparison purposes. (12) SAGE Wave 2 was conducted in 2014/2015 but data for this study was not available to the public at the time the current study was conducted. (13) Cross-sectional data from Wave 1 (2007/08) in South African adults aged 50 years and older were analysed. The sample comprised 4 037 participants,

3836 (90.9%) of whom were 50 years and older. The household response rate for South Africa was 67%, and individual response rates were 77%. (13) All participants aged 50 years and older in the selected older households were invited to complete a personal interview. Proxy respondents (through cognitive screening) were identified for a subsample unable to complete an interview. Face-to-face interviews using a standardised questionnaire were used to collect information on socio-demographic characteristics, disability, subjective well-being, and other health measures and behavioural risk factors. Post-stratified weights were used to ensure that estimates were nationally representative. (14)

5.3.2. Measurements

The following measures were used to assess quality of life and level of disability:

- Subjective well-being, or quality of life, was measured using the eight-item WHO Quality of Life Instrument (WHOQoL). (14) Outcomes from the eight questions were summed to obtain an overall WHOQoL score which was transformed to a 0–100 scale, where a score of 0 represents the worst quality of life, and a maximum score of 100 represents the highest quality of life.
- Disability level was measured using the 12-item WHO Disability Assessment Schedule (WHODAS) encompassing 6 domains of functioning; questions were summed to get an overall WHODAS score, initially a count ranging from 0 to 36. The score can be transformed onto a 0–100 scale, with 0 as no disability and 100 maximum disability. (15) The relationship between diabetes and WHOQoL and WHODAS was investigated, where diabetes status was determined through self-report, using the question ‘Has a health professional/doctor ever told you that you have diabetes?’ Additionally, participants reporting taking medication for diabetes were considered as having diabetes (or high blood sugar).

The additional variables considered were as follows:

- Selected socio-demographic characteristics were used as covariates in the analyses. These include age groups (50–59 years, 60–69 years, 70 years and older), sex (male, female), marital status (single, married/cohabiting, separated/divorced, widowed) and years of education (0–5 years, 6–12 years, ≥ 13 years). ‘Same location’ was determined using the question ‘Have you always lived in this village/town/city?’ Employment status (ever worked, never worked) and wealth quintiles (lowest to highest) were also considered. Since direct socio-economic measures are available, ethnicity, historically used as a proxy for this in SA, is excluded from the models presented below.

- Health-related variables included the use of tobacco (ever smoked, never smoked) and the use of alcohol (never drank, ever drank). A categorical variable indicating low, medium and high physical activity levels was constructed from the Global Physical Activity Questionnaire (GPAQ) included within SAGE. (16)
- Self-reported chronic conditions were assigned based on similar questions to those used for diabetes but applied to the following conditions: arthritis, stroke, angina, chronic lung disease, asthma, hypertension, cataracts and depression. A count variable was also generated for each participant (collapsed into zero, one, two or more chronic conditions).

5.3.3. Ethical clearance

SAGE Wave 1 was approved by the HSRC Research Ethics Committee (South Africa) and the National Department of Health. SAGE was also approved by the WHO Ethical Review Committee. Respondents provided written informed consent. WHO SAGE granted the investigators' permission for access to the de-identified data for secondary analysis in June 2014.

5.4. Statistical analyses

Data were analysed using R (version 3.1.3), (17) and the sampling design and probability weights were taken into account using R's 'survey' package. (18) When additional model options were required, Stata (Stata/MP 13.1) (19) was used, utilising the suite of 'svy' commands. The methodology is briefly summarised below, and some further details provided in Appendix E of the supplementary material. WHOQoL and WHODAS were analysed in turn, using generalised linear models. For WHOQoL, a standard multiple linear regression model was implemented, while for WHODAS, a zero-inflated negative binomial regression model with a log link was fitted to the data. Model choice was guided by exploration of the data and comparing a few candidates' models and confirmed to be adequate through residual diagnostic plots and comparisons of observed and model fitted scores (see Appendices C, D and H for some plots of the data and comparisons). The regression models aim to estimate the relationship between diabetes and each of the two measures of well-being, namely WHOQoL or WHODAS, while controlling for the socio-demographic, health risk behaviour and chronic conditions variables listed above.

They also aim to understand whether the relationships between these factors and the well-being measures are modified by the presence of diabetes. Two sets of p-values are reported in results for each factor: (a) The p-value for 'factor' relates to testing whether that factor is related to well-being in any way; (b) The p-value for the 'moderation effect'

relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without. Because testing for moderation is of interest, the dataset was not stratified into those with diabetes and those without, but rather all data used in the model. In the initial fitting of the models, diabetes was allowed to moderate all effects and therefore distinct ‘diabetic’ and ‘non-diabetic’ group effect sizes are reported in the tables.

To reduce the size of the model, for a given factor, when the p-value for the moderation effect was greater than 0.1, the moderation term was removed, and in these cases just one ‘all subjects’ effect size is reported below. To account for the zero-inflation for WHODAS (i.e. the excess of zero values compared to what is expected using a negative binomial distribution) an extra set of parameters was estimated and is reported. These odds ratios describe the impact of the factor on the extent of these zero values (no moderation by diabetes status allowed). Again, when the terms did not seem necessary (using a threshold of 0.1 on p-values) they were removed from the model, and therefore not all factors have associated odds ratios. List-wise deletion of observations with missing values resulted in 2848 observations for WHOQOL and 2866 observations for WHODAS. The most common missing values were: 570 for education, 492 for place of residence and 123 for physical activity.

5.5. Results

The overall prevalence of self-reported diabetes was 9.2% (95% CI: 7.8,10.9). It increased with age: from 7.1% (95% CI: 5.4,9.2) amongst 50–59-year olds, to 10.6% (95% CI: 8.0,14.0) amongst 60–69-year olds, to 12.4% (95% CI: 9.1,16.7) amongst those 70 years and older. The socio-demographic characteristics, health risk behaviours and chronic conditions of all the participants, also stratified by diabetes status, are described in Table 5-1. Half of the respondents were aged between 50–59 years (mean age 61.6 years, SD 9.5), 56% were female, 56% were in a current partnership, and 46% had less than 5 years of formal education. The majority of respondents in both groups engaged in only low levels of physical activity (60%). People in the diabetes group had at least twofold higher rates of coexisting self-reported chronic conditions (arthritis, stroke, angina, chronic lung disease, asthma, hypertension, cataracts and depression) compared to the non-diabetes group.

Table 5–1 Number and percentage of participants by socio-demographic characteristics, self-reported health behaviours and comorbidities.

*Factor	Category	n (%)		
		*All subjects	Ever diagnosed with with diabetes	No self-reported diabetes
All participants		3836 (100.0)	341 (100.0)	3495 (100.0)
Diabetes	No	3362 (90.8)		3362 (100.0)
	Yes	341 (9.2)	341 (100.0)	
Sex	Female	2146 (55.9)	228 (67.0)	1850 (55.0)
	Male	1690 (44.1)	113 (33.0)	1512 (45.0)
Age	50-59 years	1913 (49.9)	130 (38.1)	1711 (50.9)
	60-69 years	1174 (30.6)	121 (35.6)	1021 (30.4)
	70+ years	749 (19.5)	89 (26.2)	630 (18.7)
Marital status	Single	539 (14.3)	45 (13.3)	471 (14.3)
	Married/cohabiting	2108 (55.9)	170 (50.2)	1872 (56.7)
	Separated/divorced	223 (5.9)	9 (2.8)	206 (6.2)
	Widowed	900 (23.9)	114 (33.8)	754 (22.8)
Years of education	0-5 years	1418 (46.4)	95 (35.0)	1288 (47.6)
	6-12 years	1369 (44.8)	161 (58.9)	1168 (43.2)
	13+ years	269 (8.8)	17 (6.1)	249 (9.2)
Same location	Yes	2141 (68.1)	190 (66.9)	1889 (67.9)
	No	1002 (31.9)	94 (33.1)	892 (32.1)
Ever worked	Yes	3237 (85.4)	286 (84.2)	2878 (85.6)
	No	553 (14.6)	54 (15.8)	484 (14.4)
Wealth quintile	Poorest	790 (20.7)	39 (11.6)	704 (21.0)
	Second	759 (19.9)	50 (14.8)	684 (20.5)
	Middle	696 (18.2)	60 (17.6)	627 (18.7)
	Fourth	757 (19.8)	87 (25.5)	650 (19.4)
	Richest	815 (21.3)	103 (30.4)	681 (20.3)
Tobacco	No	2459 (66.4)	268 (78.8)	2188 (65.2)
	Yes	1242 (33.6)	72 (21.2)	1169 (34.8)
Alcohol	No	2765 (74.7)	294 (86.5)	2468 (73.5)
	Yes	934 (25.3)	46 (13.5)	889 (26.5)
Physical activity	Low	2154 (60.1)	220 (68.0)	1932 (59.3)
	Moderate	436 (12.2)	41 (12.8)	395 (12.1)
	High	996 (27.8)	62 (19.2)	933 (28.6)
Arthritis	No	2788 (75.3)	188 (55.1)	2600 (77.3)
	Yes	915 (24.7)	153 (44.9)	762 (22.7)
Stroke	No	3553 (96.0)	317 (93.0)	3235 (96.3)
	Yes	149 (4.0)	24 (7.0)	125 (3.7)
Angina	No	3508 (94.8)	299 (87.6)	3209 (95.5)
	Yes	194 (5.2)	42 (12.4)	152 (4.5)
Lung disease	No	3596 (97.1)	312 (91.7)	3283 (97.7)
	Yes	106 (2.9)	28 (8.3)	78 (2.3)
Asthma	No	3523 (95.1)	308 (90.5)	3213 (95.6)
	Yes	181 (4.9)	32 (9.5)	148 (4.4)
Depression	No	3596 (97.1)	322 (94.6)	3272 (97.4)
	Yes	106 (2.9)	18 (5.4)	88 (2.6)
Hypertension	No	2580 (69.7)	105 (30.7)	2474 (73.6)
	Yes	1124 (30.3)	236 (69.3)	888 (26.4)
Cataracts	No	3528 (95.6)	290 (86.8)	3237 (96.5)
	Yes	163 (4.4)	44 (13.2)	118 (3.5)

# chronic	0	1846 (50.1)	52 (15.4)	1793 (53.5)
	1	1122 (30.5)	114 (34.0)	1008 (30.1)
	2	460 (12.5)	105 (31.4)	355 (10.6)
	3+	256 (7.0)	64 (19.2)	192 (5.7)

****Sum of 'Diabetes and non-diabetes counts do not necessarily equal 'All subjects' counts because of missing data. * For a factor, sum of counts for categories do not necessarily equal 'All subjects' counts because of missing data.***

To further describe the data, see Appendix A and Appendix B of the supplementary material for summary statistics for WHOQoL and WHODAS, stratified by diabetes status and other covariates.

The associations between factors and the average WHOQoL scores, as modelled using a multivariable regression, are shown in Table 2. The additive effect or regression coefficient describes the change in the average WHOQoL score associated with a change in factor (out of the reference category into another category) – and therefore positive values indicate increases in quality of life. There was strong evidence of lower quality of life when having diabetes (-4.2, 95% CI: -9.2,0.9; p-value < 0.001). Similarly, lower scores were associated with not being in a relationship, less formal education, less wealth, lower physical activity and more chronic conditions (see effect sizes in Table5-2, all p-values < 0.02).

Table 5–2 Association of diabetes, sociodemographic characteristics, self-reported health behaviours and comorbidities with WHOQOL (0-100)

		Additive effect / regression coefficient (95% CI)			^a P-values	
Factor	Category	All subjects	Non-diabetic group	Diabetic group	Factor	Moderation effect ^b
Diabetes	No (ref)				<0.001	N/A
	Yes	-4.2 (-9.2;0.9)				
Sex	Female (ref)				0.047	
	Male	-1.4 (-2.8; -				
Age	50-59 years (ref)				0.046	
	60-69 years	1.7 (0.3;3.1)				
	70+ years	1.4 (-0.3;3.1)				
Marital status	Single	-2.6 (-4.8; -			0.016	
	Married/cohabiting (ref)					
	Separated/divorced	-1.2 (-4.2;1.8)				
	Widowed	-2.5 (-4.1; -				
Years of education	0-5 years (ref)				0.003	
	6-12 years	2.2 (0.6;3.7)				
	13+ years	5.0 (1.9;8.0)				

Same location	Yes (ref)				0.703	
	No	0.3 (-1.2;1.8)				
Past work	Yes (ref)				0.003	0.137
	No		-4.2 (-6.6; -	-1.1 (-4.6;2.3)		
Wealth quintile	Poorest		-6.8 (-9.1; -	-9.4 (-14.4; -4.3)	<0.001	0.139
	Second		-2.7 (-5.2; -	-5.9 (-12.3;0.6)		
	Middle (ref)					
	Fourth		0.5 (-1.5;2.5)	-2.6 (-6.6;1.4)		
	Richest		6.9 (4.2;9.6)	1.3 (-2.3;4.8)		
Tobacco	No (ref)				0.62	
	Yes	0.4 (-1.2;2.1)				
Alcohol	No (ref)				0.061	
	Yes	-1.8 (-3.6;0.1)				
Physical activity	Low		-3.3 (-5.3; -	0.2 (-3.0;3.4)	<0.001	0.028
	Moderate (ref)					
	High		-0.1 (-2.2;2.0)	8.1 (2.6;13.6)		
# chronic	0 (ref)				<0.001	0.009
	1		-4.6 (-6.2; -	-1.8 (-5.9;2.2)		
	2		-6.6 (-8.4; -	-0.5 (-4.8;3.9)		
	3+		-6.8 (-9.9; -	0.4 (-3.8;4.6)		

^a The p-value for 'factor' relates to testing whether that factor is related to well-being in any way. (2) The p-value for the 'moderation effect' relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without. ^b P-values are expected to be small as the only moderation effects that are included in this model are those that had p-values <0.1 in a model containing all such interactions. Model output before exclusion of terms appears in the Appendix F of the supplementary material.

There was some evidence of lower quality of life in males (p = 0.047). The impact of physical activity and number of chronic conditions differed by diabetes status (p-values: 0.028 and 0.009 respectively). High levels of physical activity appear to correspond to higher quality of life only amongst those with diabetes (high versus moderate levels: 8.1, 95% CI: 2.6,13.6. Additional chronic conditions had an effect on quality of life for all participants although the negative effect was more pronounced in those without self-reported diabetes than in those with diabetes. The results from the zero-inflated negative binomial regression model for WHODAS are shown in Table5-3.

Table 5–3 Association of diabetes, sociodemographic characteristics, self-reported health behaviours and comorbidities with WHODAS (0-36) ^c

Factor	Category	Effect sizes (95% CI)				^a P-values	
		Odds Ratio (OR)	Multiplicative effect / exponentiated regression coefficient			Factor	Moderation effect ^b
			All subjects	Non-diabetic group	Diabetic group		
Diabetes	No (ref)						
	Yes		2.1 (1.5,2.9)			<0.001	
Sex	Female (ref)					0.125	0.042
	Male			1.0 (0.9,1.2)	0.7 (0.6,1.0)		
Age	50-59 years					<0.001	
	60-69 years	0.8 (0.5,1.1)	1.1 (1.0,1.2)				
	70+ years	0.5 (0.3,0.9)	1.4 (1.3,1.5)				
Marital	Single	0.5 (0.3,0.9)		1.1 (0.9,1.3)	1.0 (0.8,1.3)	0.008	0.045
	Married/coh						
	Separated/di	0.6 (0.2,1.4)		1.0 (0.9,1.2)	0.6 (0.4,0.9)		
	Widowed	0.6 (0.4,0.8)		1.1 (0.9,1.2)	0.9 (0.7,1.2)		
Years of education	0-5 years					<0.001	0.000
	6-12 years	1.7 (1.2,2.5)		0.9 (0.8,1.0)	0.9 (0.7,1.1)		
	13+ years	2.6 (1.5,4.5)		0.6 (0.5,0.8)	1.4 (1.0,1.9)		
Same Location	Yes					0.010	
	No		1.1 (1.0,1.3)				
Past work	Yes					0.005	
	No		1.3 (1.1,1.5)				
Wealth	poorest		1.2 (1.0,1.4)			0.034	
	second		1.1 (1.0,1.2)				
	middle						
	fourth		1.0 (0.9,1.1)				
	richest		0.9 (0.8,1.1)				
Tobacco	No					0.274	0.108
	Yes			1.0 (0.9,1.2)	0.8 (0.5,1.1)		
Alcohol	No					0.006	
	Yes		1.2 (1.1,1.4)				
Physical activity	Low			1.4 (1.2,1.6)	0.9 (0.8,1.2)	<0.001	0.006
	Moderate						
	High			0.8 (0.7,1.0)	0.7 (0.5,1.0)		
	0					<0.001	0.003

# chronic	1	0.4 (0.3,0.5)		1.3 (1.2,1.5)	0.9 (0.7,1.2)		
	2	0.2 (0.1,0.3)		1.7 (1.5,1.9)	1.0 (0.8,1.3)		
	3+	0.1 (0.0,0.3)		1.7 (1.4,2.0)	1.0 (0.8,1.4)		

^a The p-value for 'factor' relates to testing whether that factor is related to well-being in any way. The p-value for the 'moderation effect' relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without. ^b P-values are expected to be small as the only moderation effects that are included in this model are those that had p-values < 0.1 in a model containing all such moderation effects. Model output before exclusion of terms appears in the Appendix G of the supplementary material. ^c for the regression model WHODAS score of 0–36 was retained.

The odds ratio is the relative change in the odds of a zero-disability score (no disability), and the multiplicative effect or exponentiated regression coefficient is the relative change in the average score amongst the remaining individuals. Therefore, an odds ratio greater than 1 and multiplicative effect less than 1 together indicate a decrease in disability with a change in the factor (out of the reference category into another category). Diabetes was associated with greater disability (multiplicative effect: 2.1; 95% CI: 1.59,2.9; p-value: < 0.001).

There was also greater disability associated with being older, being single or widowed (although there are mixed results for those with diabetes), having more chronic conditions and having lower education levels (all p-values < 0.01, see Table 3 for effect sizes). Greater disability is also associated with no past employment, and having less wealth, any alcohol use and lower physical activity levels (multiplicative effects up to 1.3; p-values < 0.05).

The impact of marital status, education, physical activity and the number of chronic conditions differed by diabetes status (p-values < 0.05). Also, an increase in the number of chronic conditions is associated with large reductions in the odds of zero disability (OR for 3+ conditions versus 0 conditions: 0.1; 95% CI: 0.0, 0.3), thus implying greater disability. There was a clear increase in the disability of the remaining individuals amongst those without diabetes (multiplicative effect: 1.7; 95% CI: 1.4,2.0) but not in those with diabetes.

5.6. Discussion

In this analysis of SAGE South Africa Wave 1 data, a 9.2% prevalence rate of self-reported diabetes was found. Individuals with diabetes had at least twofold higher rates of coexisting chronic conditions than those without diabetes. In addition, diabetes status per se was associated with poor quality of life and disability, as were socio-economic status (low education), being in a low wealth quintile, having a poor employment history, marital status (not being in a partnership), lifestyle habits (low physical activity, history of alcohol use) and co-morbid conditions. In accordance with previous studies, we found that having diabetes, (20–22) having lower formal education levels, (23–25) being in a low socioeconomic group, (26,27) not being in a marital relationship (28,29) and not having worked (30,31) were significantly associated with poor quality of life and a high level of disability, but unlike findings in other studies, (32–35) being older and being female were not associated with a high level of disability. The differences in findings in this study compared to others may relate to the use of different instruments to assess the quality of life and disability, as well as the use of diabetes-specific and generic measures across studies. In short, the study findings support a relationship between self-reported diabetes, QoL and disability, while controlling for a variety of factors such as socio-demographic characteristics, health risk behaviours and coexisting chronic conditions.

The prevalence rate of self-reported diabetes in the study reflects some factors, including the participants' low level of knowledge on diabetes, and access to diagnostic and care facilities. South African epidemiological studies have established about a 60% prevalence rate for previously diagnosed diabetes in urban areas, compared to a rate of about 15% in rural areas. The observation in our study that diabetes was more common in higher than in lower wealth quintiles supports previous findings in urban black Africans in Cape Town (36). However, our observation may similarly indicate this group's greater access to health care as well as a change in lifestyle habits, such as poor, high-sugar diets and low physical activity, often accompanying urbanisation.

Studies have shown that comorbid conditions, more than other factors, determined the quality of life of people with diabetes. For example, Rubin et al. noted that the presence of comorbid conditions could further interact with the severity of the disease and its complications to strongly influence different domains of quality of life. (37) We did not decompose the composite WHOQOL score to examine the contributions of the different domains, but the overall score suggested that the impact of comorbidities on QoL was considerable in older respondents regardless of diabetes status. A considerable proportion

of non-diabetes individuals reported more than one chronic condition (47%). The magnitude of the effect size of QoL reductions differed statistically between 4.6 and 6.8 points as the number of chronic conditions increased from one to 3+. A gradient in QoL pertaining to the number of chronic diseases in the non-diabetes group was not found in individuals with diabetes which is probably due to (1) the relatively small size sample of the diabetes group (n=341), and (2) use of a self-report questionnaire to determine the status of the chronic condition and possible underestimation of prevalence. Nevertheless, comorbidities can profoundly affect older patients' ability to care for their conditions and can pose significant barriers to lifestyle changes and accessing needed care. (38)

The results of the study showed the statistically significant impact of level of education on the quality of life of older persons with diabetes. Other studies have similarly shown a positive correlation between levels of education and quality of life. It is conceivable that those with a higher education will have a better understanding of the illness and its effect on them, will be in a better financial position to avail themselves of quality treatment and will be more likely to adhere to treatment regimens and self-management of the condition. (39)

Study participants with and without diabetes who had a high level of physical activity were found to have higher QoL scores. We are unable to determine whether this finding is due to cause or effect; it is well recognised that exercise nonetheless is associated with higher subjective well-being.(40-41) Being sedentary was found to impact the quality of life, which is consistent with other studies: for example, in older individuals, even light-intensity physical activity is related to higher self-rated physical health and psychosocial well-being. (42) Notably, the prevalence of a low level of physical activity in the South Africa data was higher er than in any other SAGE country (China, Ghana, India, Mexico, Russian Federation). (43) Although age and diabetes conspire to decrease fitness and strength, physical activity interventions improve functional status in older adults with and without diabetes. (44)

In previous studies, diabetes represented not only a risk factor for disability but also a brake on health/autonomy recovery in older persons. (45) This association is partly explained in our study by the impact of diabetes itself, sociodemographic characteristics, risk factors, health behaviours and comorbidity on disability. Reasons for this effect are not clear. Findings from an earlier study showed a 100–150% increased incidence of disability among older women with diabetes compared to non-diabetic age peers. (46). Indeed, women with diabetes had a 78% increased risk of mobility-related disability and a

65% higher risk of activities of daily living (ADL) disability. (47) In a sample of over 1000 managed-care patients with diabetes with lower formal education and low physical activity, each was associated with disability. However, the pathway between diabetes and physical disability is multifactorial, and it is not possible to differentiate cause and effect in a cross-sectional study. (47) This study investigated the relation of the overall disability score and not to domain-specific disability as they relate to diabetes and other health and socioeconomic characteristics.

The present study highlights a need to fill gaps in knowledge towards improving quality of life and meeting care needs in older adults with diabetes. A dearth of research on leading health issues such as diabetes in older adults in sub-Saharan Africa countries impacts health policy and planning. Evidence-based policy and planning on services for older clients is underdeveloped or lacking in the sub-continent, partially due to epidemiological and demographic transitions being recent and more rapid than in high-income countries. (48) Qualitative research is required to address research questions in depth relating to the impact of factors such as retirement, low income, living alone, age-friendly vs ageist attitudes of health professionals towards older clients, and the promotion of physical activity. Comparison of study outcomes on quality of life is a challenge due to the differing content validity of instruments used in different studies.

This study has both strengths and limitations. Strength is that it was able to draw on data from SAGE which has a representative sample of South Africa. Quality of life is influenced by a person's experience, beliefs, expectations and perceptions which are in turn influenced by socioeconomic status, cultural identity and literacy level. (49) It is for this reason that a standardised and well-tested instrument was used. Ethnicity may be used as a proxy for poor socioeconomic circumstances, in this study, we have a number of direct measures of socio-economic status, such as wealth quintile and education. Due to the high number of missing values (13%) this study opted not to use race which is the proxy in other similar studies. Additional limitations are that SAGE was not specific for the study of diabetes. Glycated haemoglobin data from dried blood spots collected as part of SAGE and linked to the survey data would help identify those individuals with undiagnosed diabetes and strengthen future analyses. Specific complications associated with diabetes which cause disability and impact quality of life were not recorded in SAGE. As the data are cross-sectional, causality cannot be attributed from the recorded associations between diabetes and quality of life or disability. More importantly, longitudinal data in South Africa to examine the relationship more fully are required, and further qualitative and quantitative

research methods should be used to assess and refine existing instruments, and to articulate and describe measure outcomes.

5.7. Conclusion

Diabetes is associated with lower quality of life and greater disability amongst older South Africans. Attention needs to be given to improving quality of life for older people with diabetes in South Africa through accessing appropriate health care, providing essential medicine or equipment, promoting healthy eating and physical activity behaviours, and facilitating social support networks. There is a need to develop sustainable policies for healthy ageing at the local and national levels to integrate health and older people in all policy areas. This requires identifying research priorities, allocating resources, designing and testing of new integrated care models targeted at older people within the roll-out of universal health coverage.

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Author contributions

All authors collaborated in this study. NSL, SK and MW conceived the study and MW collated the data. RK analysed the data, and all authors provided critical inputs to the analysis and interpretation of the data and results. MW wrote the initial manuscript for this study. All authors read and approved the final manuscript.

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Chapter 6

Study 3: Does social support effect knowledge and diabetes self-management practices in older persons with Type 2 diabetes attending primary care clinics in Cape Town, South Africa?

Role of the candidate

I contributed to the design and planning, preparation of materials, I participated in the training of fieldworkers and supervised them ensuring the quality of their data collection in the study sites. I monitored and cleaned the data, I collaborated with Ms. Kathryn Manning in the statistical analysis. I wrote the initial manuscript for this study.

Role of the co-authors

All authors collaborated in conceiving this study. MW and KM analysed and interpreted the data. SK and NSL were involved in the interpretation of the data and critical revision of the manuscript. All authors read and approved the final manuscript.

Publication status

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6.1. Abstract

Background

In South Africa with one of the most rapidly ageing populations in Africa despite the demographic impact of the HIV/AIDS epidemic, diabetes is a major cause of morbidity and mortality. Self-management is challenging for all those with the condition but is likely to create a higher demand for those who may have existing co-morbidities associated with age, and long-standing chronic diseases.

Objective

To determine the relationship of social support, especially that of family and friends with their self-management.

Methods

This cross-sectional study was undertaken in the Cape Town metropole primary care clinics. The sample comprised 406 people drawn from four community health centres (CHC) that are served by Groote Schuur Hospital at the tertiary level.

Results

Of the 406 participants, 68.5% were females, 60.5% were living with a family member, and almost half were married. The mean duration of diabetes from diagnosis was eight years. More than half (57.4%) had no or only primary education. Half the participants (50.2%) had poor knowledge level in relation to symptoms and complications of diabetes.

Multivariable linear regression showed older age was associated with knowledge (β : -1.893, 95% CI -3.754; -0.031) and higher income was associated with self-management practice (β : 3.434, 95% CI 0.797; 6.070). Most participants received family support to follow aspects of diabetes self-management. The ordinal logistic regression indicated that family support was positively associated with the self-management practice score for following a diabetic meal plan, taking care of feet, physical activity, testing blood sugar and handling participants' feelings about being diabetic, but not for taking medication.

Conclusions

Consideration needs to be given to developing and testing education programmes that focus on needs of older people with diabetes and emphasises the role of family and friends.

6.2. Introduction

Population ageing has been accompanied by a shift in disease profile to non-communicable diseases (NCD), increased levels of disability, and an increasing loss of physical and cognitive functioning. (1) South Africa has one of the most rapidly ageing populations in Africa despite the demographic impact of the HIV/AIDS epidemic. It is expected that, by 2025, the proportion of the older population will increase by 10.5% to reach 5.23 million. (2,3) The latest estimates are that three-and-a-half million South Africans (about 6% of the population) have diabetes, and there are many more who are undiagnosed. This number is anticipated to grow by 30% by the year 2030. (4-6) According to the WHO Global Report on diabetes in 2016, the combination of increasing prevalence of diabetes and increasing life expectancy in many populations with diabetes may be leading to a shift in the types of morbidity that accompany diabetes, such as cancers and cognitive disability. (7) Inevitably, this will place further strain on both healthcare resources and health providers.

In South Africa, 80% of the population receive their health care through the government funded public sector. (8) In general, community health centres (CHC) and smaller primary care clinics are the older persons' first point of contact with the healthcare services. These are staffed according to their size and location and provide a comprehensive package of care. The CHCs are overcrowded and poorly resourced due to the multiple disease burden, leaving limited time for the front-line health workers to deal with the management of patients with diseases such as diabetes. (8) A qualitative study found that patients with diabetes in this setting were ill-equipped to play an active role in self-care due to their limited opportunities for education and counselling. (9) In this setting too, poor control of glycaemia and hypertension together with high levels of multimorbidity are commonly encountered. (10)

Diabetes self-management practices (DSMP) form the foundation of diabetes care. These involve knowledge, skills and motivation as it requires, amongst others, adjustment of the diet, monitoring of blood glucose levels, where appropriate and an increase in physical exercise. (8,9) Sprague et al. found that the decreased priority given to patient education among older individuals, their support systems, and the healthcare community is a factor that negatively impacts their learning diabetes self-management. (11)

A number of barriers associated with ageing reduce the older persons' potential for engaging with traditional self-management education programmes such as lectures/group

sessions; for example, hearing and visual deterioration. Further self-management practice may be affected by reduced manual dexterity due to osteoarthritis which is common in this group (12,13) Therefore, older people might have fewer resources available to manage their condition than younger people and will then have a higher need for self-management support. (14) The loss of friends and family makes them more vulnerable to loneliness and social isolation. (15)

Poor social support is associated not only with an increase in mortality, morbidity and psychological distress but a decrease in overall general health and well-being. (16) Several studies have found social support vital to SMP in people with chronic diseases. (17-19) Social support can be either emotional or physical. Emotional, social support is defined as the degree to which interpersonal relationships serve the purpose of providing emotional, informational or influential quality of life for the individual. (20) Physical support is defined as the forms and numbers of social relationships (marital status, the number of friends) and the degree of connection between these relationships (social network).

Most frequently social support for persons with diabetes covers aspects of active support and emotional encouragement with taking medications, monitoring blood glucose, foot and eye care, following diabetic meal plans and increasing physical activity. (21) This study was undertaken in older people with diabetes in South Africa to examine their knowledge about living with and managing their diabetes; and to determine the relationship of social support, especially that of family and friends with their self-management.

6.3. Methods

6.3.1. Study design and selection of participants

This cross-sectional study was undertaken in the Cape Town metropole where working class people receive care through a network of primary care clinics. Eighteen community health centres (CHCs) formed the sampling frame for the study on the basis of them being served by Groote Schuur Hospital at the tertiary level. Four CHCs were selected based on population density of the older population in their drainage area as reported in the statistical censuses of 2011. (3)

As a diabetes register system does not exist in the metropole, the population of adults (>60 years) with diabetes within it is not known. Consequently, calculation of a representative sample size was not possible. A purposive convenience sample of (n=406)

was drawn by a random sampling technique from those who attended the four CHCs with approximately (100) participants from each clinic.

6.3.2. Instruments

We adopted a validated questionnaire that has been tested in older adults in many low and middle-income countries including South Africa. (21-27) We piloted the appropriateness, reliability and clarity of the questionnaire in a sample of 40 participants (10%). The English version questionnaire was translated to Xhosa and Afrikaans, the languages of the study area. We used the Social Support subscale of the Diabetes Care Profile (DCP). (28) It includes twelve questions related to family and friend social support. Each question consists of one item making it a total of 12 items. Each item is measured on a 6-point Likert scale (Appendix A: supplementary materials).

6.3.3. Data collection

Six fieldworkers were responsible for data collection using questionnaires and a review of records for HbA1C and fasting blood glucose results. They were trained in the administration of data collection tools, research ethics and an approach to interviewing older persons. The fieldworkers were closely supervised by the research team to guarantee the quality of data collection. Signed consent to participate in the study was obtained before administration of the study questionnaire (Appendix B :supplementary materials-. A random sample of ten questionnaires was checked for completeness and correctness.

6.4. Data analysis

For each respondent, a single knowledge score (K) was calculated based on 11 questions. One point was allocated for each correct answer. Similarly, respondents' diabetes self-management practice scores (DSMP) were calculated for each correct answer.

All points were summed to obtain a practice score for each respondent, ranging from 0-11. The questionnaire measures the degree to which the respondent perceives their family and/or friends provide support. The social support subscale was calculated into a summative score by combining variables with Likert scale questions (12 items) that measured the reported level of tangible and emotional social support (SS) received from either family or friends. Reliability measured for the 12 items (Cronbach's alpha) was 0.852.

The K, DSMP and SS scores were each converted to three indices ranging from 0-100. An overall HbA1c level in the last three visits was calculated as the average of the three

separate readings. Glycaemic control was considered good, acceptable or poor when the HbA1c level was lower than 7.5 between 7.5-8.5 % or greater than 8.5%, respectively. (29) Similarly, three blood glucose readings were captured from the database. Data was managed and analysed using SPSS Statistics version 23. (30) and Stata 15.1 (Stata Corp College Station, TX, USA). Categorical data was summarised as frequency and proportions, and continuous data as mean and standard deviation (SD). Unpaired t-tests and one-way analysis of variance (ANOVA) were used to compare knowledge, self-management practice and social support scores between two and three (or more) group variables respectively.

Ordinal logistic regression was used to determine associations between outcomes (knowledge, self-management practice) with components of social support scale. Multivariable linear regression was used to evaluate the associations between outcomes (knowledge, self-management practice) and sociodemographic variables (gender, age group, education level, income, living environment, glycaemic control, and social support). Variable selection for the linear regression analysis was based on previous literature which suggested that the variables may be associated with main outcomes. Regression estimates were reported with 95% CIs. Statistical significance was indicated by $p < 0.05$.

6.5. Results:

6.5.1. Descriptive and bivariate analysis.

Patients' demographic profile and clinical characteristics.

Socio-demographic and clinical characteristics of the study sample are presented in table 6-1. Of the 406 participants, 68.5% were females, 60.5% were living with a family member, and almost half were married. Two hundred thirty-three (57.4%) had less than 7 years of education. Unsurprisingly most of the participants were pensioners 374 (92%) and 348 (84%) reported family income \leq R 1500. (US\$107).

The mean duration of diabetes from diagnosis was eight years. Sixty-two percent were using oral therapy for glycaemic control, 31% combined insulin and oral agents and 7% insulin alone. The majority were taking medication for other conditions: 306 (75.4%) for hypertension, 138 (34%) for other chronic diseases and 61 (15%) for heart problems. The HbA1c was higher than 8.5% in nearly 185 (47.7%) of the participants, $<7.5\%$ in 112 (28.9%) and 7.5-8.5% in 91 (23.4%).

There were relationships between age group and a history of being hospitalised in the past 12 months (P-value 0.042). Women were more likely than men to have had low and high blood sugar (21% vs 11%, $p=0.016$) and (53% vs 37% $p= 0.004$) respectively.

Table 6-1 Socio-demographic and clinical characteristics of the study participants

			Age group	Gender
Variable	N	(%)	P-value	P-value
Socio-demographic characteristics				
<i>Age group (Years)</i>				
60-69	257	63.5%		
70-79	121	29.8%		
80 or above	28	6.7%		
Sex: Female	278	68.5%		
<i>Marital status</i>			0.000	0.000
Single	44	10.7%		
Married	209	51.9%		
Divorced	38	9.2%		
Separated	27	6.5%		
Co-habiting	88	21.7%		
<i>Level of Education</i>			0.35	0.002
≤ 7 years	233	57.4%		
9-12 years	162	39.9%		
≥ 13 years	11	2.7%		
<i>Employment status</i>			0.315	0.109
Pensioner: Yes	374	92.0%		
<i>Who are you living with</i>			0.000	0.000
Spouse	52	12.8%		
Family member	246	60.5%		
Friend	9	2.2%		
Alone	25	6.3%		
More than one	74	18.2%		
<i>Monthly family income</i>			0.113	0.20
≤R1 500	348	85.7%		
>R1 500	58	14.3%		
Clinical characteristics				
<i>Diabetes duration</i>			0.050	0.28
Less than 5 years	125	31.0%		
5-10 years	158	39.2%		
>10 years	120	29.7%		
Taking prescribed medication: Yes	403	99.3%	0.90	0.24
<i>Type of prescribed medication</i>			0.39	0.80
Insulin injections	28	6.9%		
Pills	250	62.0%		
Both	125	31.0%		
Have you experienced low blood sugar: Yes	73	18.0%	0.31	0.016
Have you experienced high blood sugar: Yes	195	48.0%	0.088	0.004
Receiving medication for hypertension: Yes	306	75.4%	0.46	0.006
Receiving medication for heart disease: Yes	61	15.0%	0.33	0.78

<i>Receiving medication for other chronic disease(s): Yes</i>	145	35.7%		0.21	0.27
<i>Hospitalised in past 12 months: Yes</i>	24	5.0%		0.042	0.36
<i>Glycaemic level (HBA1c)</i>				0.45	0.22
<i><7.5%</i>	112	28.9%			
<i>7.5-8.5%</i>	91	23.5%			
<i>>8.5%</i>	185	47.7%			

Knowledge, diabetes self-management practices, Social support scores

Overall the level of knowledge was poor in 204 (50.2%) (Table 6-2). The deficiencies were particularly noticeable in relation to symptoms of diabetes and complications of diabetes and hypertension. There was a better level of knowledge about aspects of self-management e.g., a healthy diet and foot care; with 61.3% and 64.8% of respondents correctly answering questions about walking barefoot and daily foot inspection respectively (Figures 6-1a and 6-1b).

Table 6–2 Knowledge, self-management practice, social support scores.

		N	%
Knowledge (K)	Poor K (0-14)	204	50.2%
	Good K (15-30)	202	49.8%
	Total	406	100.0%
Self-management practice (SMP)	Poor SMP (1-5)	162	39.9%
	Good SMP (6-11)	244	60.1%
	Total	406	100.0%
Social support (SS)	Poor Social support (0-3.5)	94	23.2%
	Good SS (4-6)	312	76.8%
	Total	406	100.0%

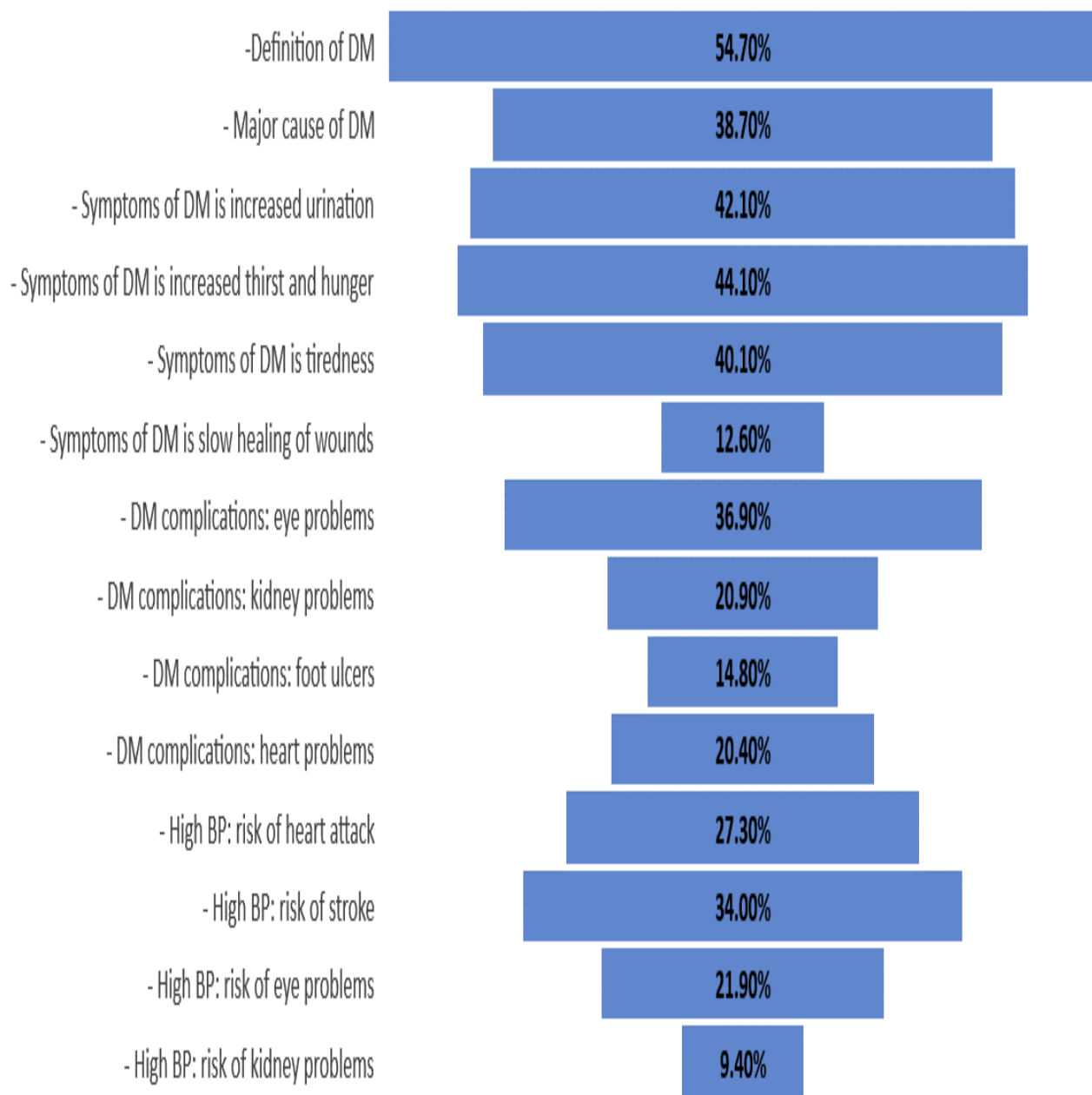


Figure 6-1a Distribution of correct answers to questions on Knowledge on Symptoms and Complications of Diabetes and hypertension (n = 406)

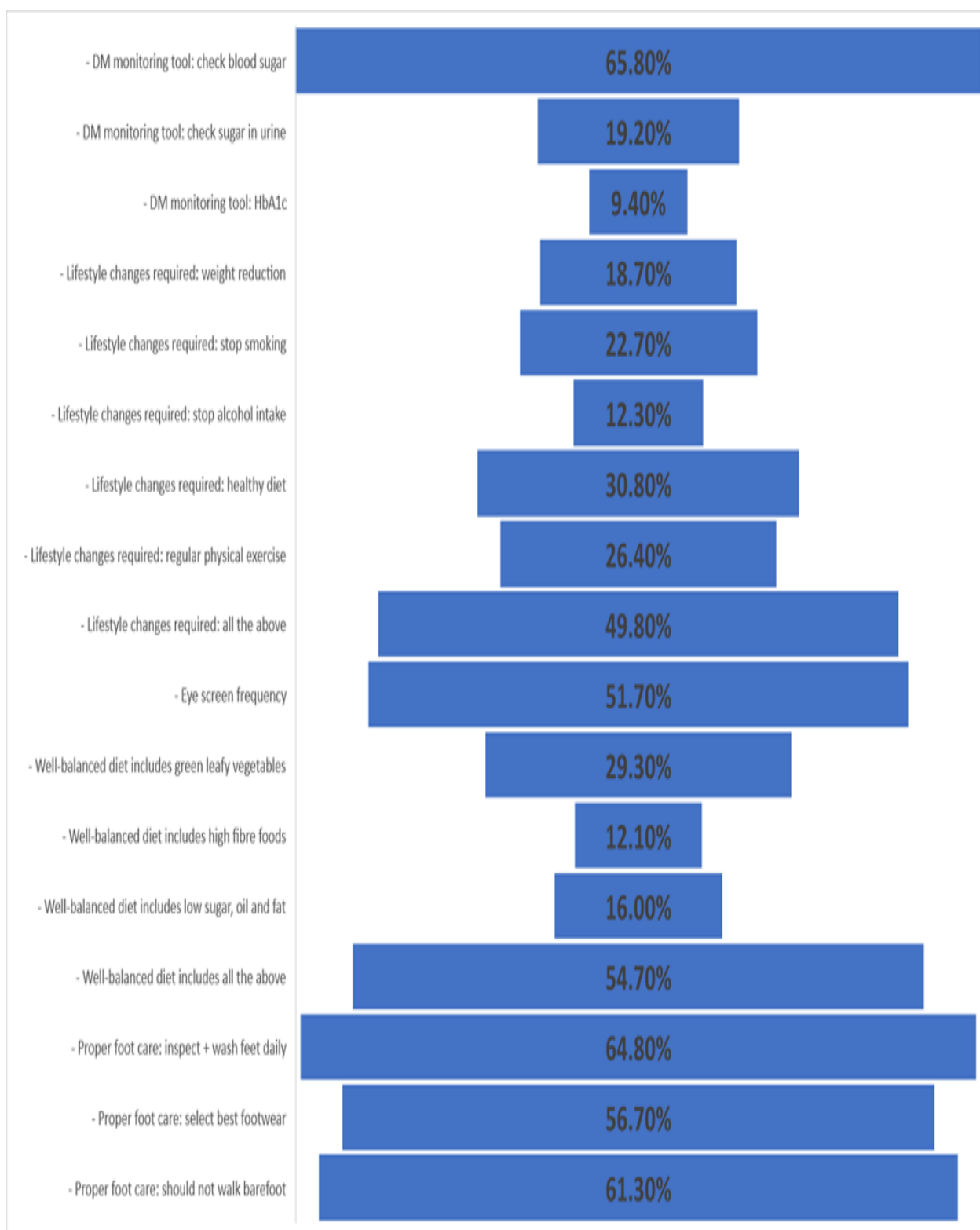


Figure 6–1b Distribution of correct answers to questions on diabetes self-management knowledge (n = 406).

Over three-quarters of participants (312 (76.8%)) had good social support (Table 6- 2). The majority of participants agreed that their family supported them to follow all aspects of self-care included in the questionnaire and encouraged them in managing their diabetes. Similarly, 233 (57.5%) were assessed as having a good level of physical exercise and almost two-thirds (262) of the participants were following a diabetic eating plan (Table 6- 3).

Only 74 (18.4%) reported that their family nagged them about their diabetes and 71 (18%) reported that their family felt uncomfortable about them because of their diabetes (Table 6-4). The mean diabetes knowledge, self-management practice and social support scores of the participants by socio-demographic and clinical characteristics are presented in Table S1 and S2 respectively in supplements. The mean knowledge score was significantly lower for a single (41.2 (SD= 2.9)) compared to married respondents (46.7 (SD =12.5)) or those in a companionship (49.4 (SD =12.7)). The mean knowledge score was greater for participants with higher education level and those who had experienced high or low blood sugar ($p=0.005$ and $p=0.001$ respectively), and those receiving medications for chronic diseases other than hypertension ($p= 0.038$) than their counterparts.

Table 6- 3. Self-management practice of lifestyle risk factors.

		N	%	Age group	Gender
				P-value	P-value
Physical activity in the past week	Never (0 days)	20	4.9%	0.49	0.97
	Seldom (1-2 days)	77	19.0%		
	Sometimes (3-4 days)	75	18.5%		
	Often (5-7 days)	233	57.5%		
Following diabetic eating plan	Yes	262	64.5%	0.51	0.85
	No	144	35.5%		
How often do YOU test your blood glucose	Occasionally or 1-2x per week	163	40.1%	0.64	0.004
	Once a day	60	14.8%		
	3-4x per day	29	7.1%		
Smoking status	Currently smoking	112	27.7%	0.007	0.000
	Previously smoked	147	36.3%		
	Never smoked	146	36.0%		

Being hospitalised in the last 12 months was associated with higher mean self-management practice than those not hospitalised (54.5 (SD =17.7) vs 43.6 (SD = 22.1) $p=0.042$). However; receiving medication for heart disease was associated with a lower

mean score for self-management practice than their respective counterparts (48.7 SD =18.8 vs 54.7 SD =17.9) $p=0.017$). The social support score means also differed significantly with living arrangements; it was lowest in those living with a spouse (67.7 SD = 21.0), intermediate in those living alone (75.0 SD =21.5) and highest in those living in multiple household members (82.3 SD =18.0 $p = 0.001$). On the other hand, there were no significant associations between diabetic knowledge, self-management practice and social support score with duration of diabetes, the type of medication used to treat diabetes, or receiving treatment for hypertension.

6.5.2. The multivariable regression models.

The ordinal logistic regression models of knowledge, self-management practice and the components of social support scale are given in Table 6-5. The table shows the effect of the K and SMP indices on the 12 individual SS components, which were measured on a Likert scale. Social support was positively associated with the self-management practice score for following a diabetic meal plan, taking care of feet, physical activity, handling participants' feelings about being diabetic and testing blood sugar, but not for taking medication. Family and/or friend emotional support (nagging, encouraging /reassuring and handling feelings about being diabetic) were positively associated with knowledge score. Multivariable linear regression analysis (Supplement, Table 3 and 4) showed older age was associated with knowledge (β : -1.893, 95% CI -3.754; -0.031) and higher income was associated with self-management practice (β : 3.434, 95% CI 0.797; 6.070). There were no significant associations of socio-demographic variables, HbA1c and social support with knowledge or self-management practice

Table 6–4 Social support assessment of the Study Participants (n = 406).

(My family or friends help and support me a lot to):	Strongly Disagree (N) %	Somewhat Disagree (N) %	Neutral (N) %	Somewhat Agree (N) %	Strongly Agree (N) %
a. Follow my meal plan.	(40) 10.0%	(11) 2.7%	(27) 6.7%	(42)10.4%	(279) 69.4%
b. Take my medicine.	(43) 10.6%	(10) 2.5%	(33) 8.1%	(30) 7.4%	(275) 67.7%
c. Take care of my feet.	(61) 15.3%	(20) 5.0%	(34) 8.5%	(45) 11.3%	(226) 56.5%
d. Get enough physical activity.	(71) 17.7%	(25) 6.2%	(24) 6.0%	(68) 17.0%	(196) 48.9%
e. Test my sugar.	(95) 24.4%	(9) 2.3%	(40) 10.3%	(24) 62%	(175) 45.0%
f. Handle my feelings about diabetes.	(35) 8.7%	(11) 2.3%	(22) 10.3%	(66)16.4%	(264) 65.7%
My family or friends:					
a. Accept me and my diabetes.	(1) 0.2%	(1) 0 .2%	(2) 0.5%	(4) 1.0%	(392) 65.7%
b. feels uncomfortable about me because of my diabetes.	(296) 73.4%	(13)3.2%	(8) 2.0%	(13) 3.2%	(71) 17.6%
c. Encourage or reassure me about my diabetes.	(22) 5.5%	(4)1.0%	(19) 4.7%	(33) 8.2%	(320) 79.4%
d. Discourage or upset me about my diabetes.	(342) 84.9%	(18) 4.5%	(5)1.2%	(20)5.0%	(14)3.5%
e. Listen to me when I want to talk about my diabetes.	(23) 5.7%	(7) 1.7%	(38) 9.4%	(30)7.4%	(293) 72.7%
f. Nag me about diabetes.	(286) 71.0%	(20)5.0%	(21) 5.2%	(33) 8.2%	(41)10.2%

Table 6–5 The ordinal logistic regression models of knowledge, self-management practice with the components of social support scale.

	Knowledge Index					Self-Management Practices Index					
Parameter Estimates				95% Confidence Interval					95% Confidence Interval		
	Estimate	Std. Error	Sig.	Lower Bound	Upper Bound	Estimate	Std. Error	Sig.	Lower Bound	Upper Bound	Pseudo R2
My family or friends help and support me a lot to:											
a. Follow my meal plan.	.000	.008	.972	-.016	.015	.024	.006	.000	.012	.037	0.023-0.053
b. Take my medicine.	.000	.008	.970	-.015	.016	.006	.006	.273	-.005	.018	0.001-0.003
c. Take care of my feet.	-.004	.007	.563	-.017	.009	.018	.005	.000	.008	.028	0.014-0.037
d. Get enough physical activity.	-.002	.006	.769	-.014	.010	.017	.005	.000	.008	.027	0.013-0.035
e. Test my sugar.	-.011	.007	.114	-.024	.003	.012	.005	.017	.002	.021	0.009-0.024
f. Handle my feelings about diabetes.	.015	.007	.042	.001	.029	.021	.006	.000	.010	.032	0.022-0.051
My family or friends:											
a. Accept me and my diabetes.	-.164	.298	.582	-.749	.421	.250	.212	.240	-.167	.666	0.004-0.019
b. feels uncomfortable about me because of my diabetes.	-.003	.009	.721	-.022	.015	.001	.007	.860	-.012	.015	0.00-0.001
c. Encourage or reassure me about my diabetes.	.033	.012	.006	.009	.056	.013	.009	.166	-.005	.031	0.016-0.030
d. Discourage or upset me about my diabetes.	-.020	.019	.301	-.057	.018	.001	.014	.925	-.027	.030	0.002-0.004
e. Listen to me when I want to talk about my diabetes.	.010	.009	.295	-.009	.028	.004	.007	.548	-.010	.018	0.002-0.005
f. Nag me about diabetes.	.023	.009	.013	.005	.040	-.001	.006	.829	-.013	.010	0.009-0.020

6.6. Discussion

In this study, half of the participants had a poor knowledge about diabetes and its complications. Just under two-thirds were assessed as having a good level of physical exercise and two-third of the participants were following a diabetic eating plan. Three quarters perceived that their family supported them to follow all aspects of self-care management. Being in the high-income group was associated with good level of self-management practice. Finally, social support was positively associated with both knowledge and a number of self-care aspects. The deficiencies noted in the participant's knowledge relating to the complications of diabetes and hypertension are alarming.

It suggests that whatever diabetes educational opportunities participants, particularly the older group, have been exposed to, have not been effective. There are many potential reasons for this. For instance, the high patient numbers and multiple disease burden in primary care clinics, are likely to negatively impact on the time available for patient education by health promoters, nurses or doctors. (29,30) Other factors to be taken into consideration include lack of attendance at educational sessions when they take place, communication barriers, such as poor hearing, lack of concentration, inability to engage with the material presented and use of didactic modes of communication. (31)

The participants' seemed to have a better knowledge of self-management practice such as foot care and healthy eating. Whether this is because these messages are practical and easier to convey or that the information comes from multiple sources and not only health care workers is uncertain.

To date, there is a scarcity of evidence regarding diabetes self-management education and support in older adults. (32) Some studies that included older persons suggest that this group needs diabetes self-management education that stresses problem-solving skills rather than "rules" to follow. For example, The Diabetes Education and Self-Management Ongoing and Newly Diagnosed (DESMOND) educators observed that older persons contributed to the group and brought valuable experience, but that they may have required a different approach at times. (33)

Sinclair et al. reported that older people benefitted more than middle-aged people from a highly-structured group diabetes self-management education intervention with embedded cognitive behavioural strategies compared to standard group education or individual sessions with dietitians and nurse educators. (34) As older persons may have difficulties

concentrating and understanding abstract concepts, there is a need for educational material to be provided in the form of simple messages, delivered in a style that engages the person with diabetes and is personalized to their needs, with the emphasis on what they need to know, rather than all there is to know about diabetes. (35,36) Notably, these concepts to enhance knowledge and self-management practices are not unique to the older person with diabetes and are relevant in all societies. Income and financial issues are possible barriers to optimum self-management for many older diabetic patients because of the costs of blood glucose testing, medication and following diet recommendations. (37)

We found that almost 75% of participants perceived that their family supported them to follow all aspects of self-care management. This may be of an advantage in many cultures such as in South Africa where strong family relationships and family caring are important and highly valued. (38) A cohesive and supportive family may provide older diabetic patients with an opportunity to express feelings and fears. (38) When DSMP is reviewed as a shared responsibility with the whole family, older persons may adopt DSMP activities more easily and feel more self-confident in managing diabetes. (39,40) As family-focused interventions may be more effective in improving DSMP performance than individual-focused interventions (41,42) including family members or friends in education programmes should be considered. (43)

The shortage of professional health care workers in South Africa highlights the need to develop alternative delivery models for education and self-management for people with diabetes who attend primary care services. These include using the services of community health workers (CHWs) and peer supporters and should draw on previous lessons learnt. (44) For example, while a pragmatic trial of a group diabetes education programme led by health promoters in Cape Town improved blood pressure, but not self-efficacy, locus of control or glycaemia control; process evaluation suggested numerous problems.

These were finding suitable space for group education, with patient attendance and with full adoption of a guiding style by the health promoters. Thus, groups held outside of primary care clinics in the community and led by well-trained CHWs or peers may be a better option, so too may the active participation by family members in these groups. (44) In addition, the emphasis on diabetes prevention programs in middle-aged people must be highlighted, because it will enable the next generation of older persons to live with a reduced diabetes burden. (45) For these reasons, South Africa's health care system needs

to transform its services offered to the large number of older persons to reduce health care costs and ensure quality of life.(46)

6.6.1. Study strengths and limitation.

This study contributes to an understanding and fills a gap in the current knowledge, relating to diabetes self-management practices, and perceived social support from family and friends and diabetes care for older people in South Africa. However, the study has some limitations. First, as a cross-sectional survey design, our study could not assess cause and effect. Second, the measurements of self-report rather than direct observation of self-care practices are recognised as a limitation. In addition, the use of a convenience sample drawn from a population who attend a diabetes clinic excludes those who did not attend. Third, our study was limited to one region and may not be representative of all older South Africans with diabetes. Future research should focus on developing and evaluating family/friends focused community-based multi-disciplinary education programmes to improve DSMP among older individuals attending primary care clinics with a view to enhancing the quality of life and to reduce disability. (47)

6.7. Conclusions

Consideration needs to be given to developing and evaluating education programmes that focus on the needs of older people with diabetes mellitus and emphasises the role of family and friends. However, it is imperative to introduce programmes at a younger age so that diabetes self-management strategies are embedded as a life course perspective to enhance positive outcomes for persons living with diabetes.

Ethics approval and consent to participate

The study was approved by the Human Ethics Committee of the University of Cape Town. (HEC REF: 21/2013). This research was conducted in accordance with the Declaration of Helsinki and written consent was obtained from each participant.

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Authors' contributions

All authors collaborated in conceiving this study. MW and KM analysed and interpreted the data. MW wrote the initial manuscript for this study. SK and NSL were involved in the interpretation of the data and critical revision of the manuscript. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that they have no competing interest.

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Chapter 7

Study 4: current policies and practice for the provision of diabetes care and self-management support programmes for older South Africans

Role of the candidate

I, Professor Levitt and Dr Kathy Murphy conceived of this review, I collected the data and analysed the data together with Dr Murphy. I wrote the initial manuscript.

Role of the co-authors

All NSL SK contributed to interpretation of the data, preparation of the manuscript and approved the final manuscript.

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7-1 Abstract

Introduction

One of the most important primary health challenges currently affecting older people in South Africa (SA) is the increasing prevalence of non-communicable disease (NCD). Research is needed to investigate the current state of care and self-management support available to older diabetic patients in SA and the potential for interventions promoting self-management and community involvement.

Methods

This study aimed to review current policies and programmes as they relate to older people with diabetes. It involved a documentary review and qualitative individual interviews with key informants in the health services and Department of Health.

Results

Several national initiatives have sought to advance the health of older people, but they have only been partially successful. There are however multiple efforts to re-orientate the healthcare system to focus more effectively on NCDs, which benefit older patients with diabetes. The establishment of community-based services to provide self-management support, promote health and ease access to medicine helps overcome many of the commonly cited barriers to care experienced by older patients. What may be equally important is that practitioners gain the communication skills and educational resources to effectively educate and counsel patients on lifestyle behaviour change and self-care management.

Conclusion

This paper alerts policymakers and clinicians to some of the specific issues considered to be pertinent and important in the care and management of older diabetic patients. Many of these would also be applicable to older patients with other chronic conditions.

7.2. Background

South Africa is undergoing the epidemiological transition typical of many low-to-middle income countries. Rapid urbanisation, attendant changes in diets and levels of physical activity along with population ageing have resulted in a significant increase in the burden of non-communicable disease (NCD), alongside a high prevalence of HIV, and violence and injuries, maternal and child mortality (1).

Diabetes is associated with high levels of morbidity, multiple therapies and functional deterioration and as such, poses challenges to health care systems, individual patients and their families. (2) Older persons are defined as individuals who are 60 years and older. (3) For the older person, the complexity of managing diabetes is often exacerbated by increased frailty, functional limitation, changes in mental health and increased dependence (2) Social issues such as loss of independence, removal from the home environment and institutionalisation also commonly affect the quality of life and wellbeing of older people with diabetes and their ability to self-manage the condition. (3) Access to care is also often a challenge for older people, because of a lack of or the cost of transport, particularly in rural areas, as well as increasing physical disability and child caring responsibilities. Overcrowding and long waiting times at health facilities, fragmented or siloed care for multiple morbidities and poor communication with healthcare providers are further barriers to care. (4-5) All these issues impact on the capacity of older diabetes patients for self-care and glycemic control. They also contribute to poor health outcomes and the high costs of diabetes treatment and care. Interventions which address the unique needs of older people with diabetes may, therefore, be warranted and may help reduce diabetes-related morbidity and associated healthcare costs. (6)

The only SA document which specifically addresses the unique needs of the older diabetic patient is the 2017 Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) guideline. (7) According to the guidelines, the comprehensive goals of diabetes management in older individuals are not significantly different from those of their younger counterparts, with glycaemic control and the reduction of other risk factors for macrovascular and microvascular disease remaining key factors for optimal management. Lifestyle modification is still advised and if there are no contra-indications, physical activity should be an integral part of the treatment plan. The SA guidelines are in line with the treatment recommendations in the Position Statement on behalf of the International Association of Gerontology and Geriatrics, the European Diabetes Working Party for Older

People, and the International Task Force of Experts of Diabetes. (8) They recommend regular comprehensive geriatric assessments to identify related functional loss and the impact of disability, as well as regular screening for mood disorder and nutritional assessments.

Research is needed to investigate the current state of care and self-management support available to older diabetic patients in SA, the degree to which their needs are being met and the potential for interventions promoting self-management and community involvement in line with WHO Innovative care for chronic conditions (ICCC) Framework(9) This study aimed to review current policies, programmes and any other interventions as they relate to older people with diabetes with a view to assess the potential for the development of a self-management programme for older persons attending, public sector primary health care services in Cape Town, South Africa.

7.3. Methods

This study followed a qualitative, exploratory, descriptive design, using the methods of documentary review and individual interviews with key informants.

1. Documentary review

A search was conducted with the aim of sourcing all documents which addressed the health needs of older people in South Africa, and more specifically, the needs of older people with diabetes. These included national and provincial government policy and planning documents, clinical guidelines for the treatment and management of diabetes, as well as commentaries or reviews of the SA health services compiled by civil society stakeholders/organisations. Relevant documents were sourced from SA government websites and internet searches using the keywords “older people in South Africa and health; SA policy on ageing; older persons and diabetes in SA/Western Cape.” Also, several documents were provided by the key informants, either during the interviews or subsequently by email.

2. Key informant interviews

Qualitative, individual, face-to-face interviews were conducted with purposively selected key informants, who were chosen for their knowledge of the topic and their responsibility for implementation of national/provincial policies or programmes relating to diabetes in the public health sector, or for clinical practice in primary care clinics. Individuals were identified with the assistance of the Head of the Endocrinology Department at Groote Schuur hospital in Cape Town. Interviews were conducted in a private room at the

department and in three referring public sector, primary healthcare clinics (Retreat; Woodstock, Heideveld). An interview guide was developed to explore informants' knowledge of and views regarding diabetes self-management programmes for older persons attending, public sector primary health care services (Appendix A). The interviews were about 30-45 minutes in duration and were conducted from December 2016 to April 2017. They were audio-taped and then transcribed verbatim.

7.4. Data analysis

The method of qualitative content analysis was used to describe and interpret the data from the selected documents and the individual interviews. (10) The analysis proceeded through the following steps: 1) reading through all the interview transcripts and documents to get a sense of the whole 2) systematically identifying and coding relevant 'meaning units' and developing a coding list 3) collating the coded data into categories and grouping these under higher order categories or more abstract headings 4) the coherent integration of the analysis into a descriptive account of the mainly manifest content of the data 5) the selection of compelling quotes to illustrate and summarise the findings in tables. In the initial stages, the authors MW and KM analysed the data independently and after that, cooperated closely in developing an interpretive and descriptive account of the findings for the manuscript.

ETHICS

The study was approved by the Human Ethics Committee of the University of Cape Town. (HEC REF: 21/2013), and written consent was obtained from each participant interviewed.

7.5. Findings

The findings below integrate information sourced through the documentary review and findings from the key informant interviews. They describe current policies, plans, guidelines and programmes which have relevance to the health needs and provision of care of older people with diabetes. Interviews were conducted with a total of 5 individuals: a senior official and policymaker in the Department of National Health; a Director of Chronic Disease in the Western Cape Provincial Health Department; a family physician responsible for a primary care clinic in the Cape Town metro, a medical officer and a health promoter. The researchers have approached other key informants but unfortunately, they didn't respond regardless to the emails reminders that were sent to them weekly. The key

to the labelling of these key informants is found in Table 1. The documents that were included in the documentary review are listed in Supplementary Table 1.

Table 7-1 The key to the labelling of key informants

Key informant	Position
KI 1	Director of Chronic Disease programme in the Western Cape Provincial Department of Health
KI 2	A senior official in the National Department of Health, responsible for NCD health policy and guidelines
KI 3	A family physician working in the primary care clinic in the Cape Town metro
KI 4	Operational manager of primary care clinic in the Cape Town metro
KI 5	Health Promoter in primary care clinic in the Cape Town metro

1. Theme one: National initiatives for the advancement of the health and wellbeing of older persons in South Africa

An important milestone in advancing the interests of older people as a distinct group occurred in 2002 when SA signed the Declaration on Ageing at the Second World Assembly on Ageing in Madrid. (11). This served as the basis for the 2002 SA Plan of Action of Aging. The plan gives government the primary responsibility for implementation of the recommendations, but stressed that partnerships with civil society, academic institutions, the private sector and older persons themselves are critical to achieving its goals. (11) In the section on health, the plan recommends that the National Department of Health (NDOH) review all health policies and strategies to ensure that services are more responsive to the specific needs of older people. There are specific recommendations that the NDOH should develop and implement programmes for the management of chronic health conditions that are more prevalent in old age and for the promotion of healthy and active lifestyles among older individuals to prevent illness and functional decline and in so doing, generally improve quality of life. (12).

The next important national intervention was the passing of the Older Person's Act in 2006, which provides for the protection of the elderly's rights and the criminalisation of abuse. This was followed by programmes to educate the public on the rights of older persons in all provinces, the development of a national protocol on the management of abuse of older persons; the drawing up of minimum standards for residential care and plans to promote

the respect of older people at government service points (Operation Dignity). (13) A parliamentary briefing by the Department of Social Development in 2013, provides further insight into the implementation of the Act and its challenges. (14)

According to Goodrick, (15) these initiatives have only been partially successful in putting the health and welfare of older people higher on the national agenda and in improving the material and social well-being of the older South African population. This, he argues, is attributable primarily to policy prioritising the country's young population, the focus on HIV/AIDS and an overall lack of awareness of the potential socio-economic and fiscal implications of population ageing. In his view, until ageing concerns are mainstreamed in policies, the development of services and facilities for the aged will remain relatively neglected. Further, a 2013 UN review of the Madrid International Plan of Action on Ageing concluded that there had been a decline in the well-being of older persons in Africa, including South Africa since 2008. this is due mainly to demographic shifts, an increased burden of disease and inadequate government intervention. (16)

2. Theme two: National government action to address diabetes and other NCDs

The NDOH has drafted a Strategic Plan for the Prevention and Control of NCDs (2013), which is closely aligned to UN/WHO recommendations and places a strong emphasis on intervention in three distinct areas. Evidence suggests can produce rapid gains in reversing the NCD epidemic: 1) The prevention of NCDs and the promotion of health at a population, community and individual level to address the broader social determinants of health; 2) improved control of NCDs through the strengthening of the primary health system; and 3) comprehensive monitoring of NCDs and their risk factors.(17) At the population level, legislative and fiscal measures are in place to control tobacco, salt, trans-fats and sugar in beverages. Policy development on alcohol has, however, been slow, mainly because of opposition from the industry. These interventions have had a positive impact, but more aggressive efforts are needed to ensure compliance. (18) Several aspects of NCD surveillance need strengthening, notably the quality and completeness of information on mortality, the more regular monitoring of NCD risk factors and quality of care. (18)

2.1. Primary Health Care Re-engineering policy

As part of the NCD plan, the NDOH has introduced the Primary Health Care Re-engineering policy with the aim of strengthening the response to NCDs at this level in the health system. The policy envisages health facility-based chronic care teams working with

Ward-based Outreach Teams (WBOTS), comprising nurses and community health workers (CHWs) to deliver integrated NCD services, including follow up and ongoing support to individuals in their households and communities. According to the SA Health Review (SAHR), while there has been an increase in the number of primary healthcare facilities with functional chronic care teams and WBOTS, at this point, it is not clear how widely CHWs have been deployed and how well prepared they are for scaled-up community-based NCD prevention and management. (19) Several studies in SA have demonstrated the capacity of CHWs to effectively execute specific NCD related tasks, such as screening and health education, but they have also shown that there is a wide variation in their scope of practice and level of training, insufficient support and supervision and a lack of resources and supplies necessary for the performance of many of their tasks. (19-20) Generally, patients still rely heavily on health facilities for NCD management and are still accessing healthcare at inappropriate levels. (20-22). Quality improvement interventions in public health facilities are being implemented, to meet the quality norms and standards to varying degrees. These include: (1) the scaling up of the Ideal Clinic model; (2) infrastructure improvement across the health sector; and (3) implementation of the WHO's Workload Indicators for Staffing Needs instrument. From a treatment perspective, the integrated chronic disease management (ICDM) model is a central part of the ideal clinic and re-engineering of primary care as a vehicle to improve the management of chronic conditions including NCD (23,24)

2.2. Practical Approach to Care Kit (PACK)

A further aspect the re-engineering strategy is the implementation of the Practical Approach to Care Kit (PACK) in all primary care facilities. PACK is a programme comprising clinical guidance, an implementation strategy, health systems strengthening and monitoring and evaluation components. PACK Western Cape Adult started as a research project in the Eden district of the province and was subsequently launched as a provincial programme in March 2014 (21). These are integrated, evidence-based clinical guidelines, which aim to improve the diagnosis and management of the most common conditions in primary care, including NCDs. A process evaluation in 2016 showed that there was widespread use of the guideline and that it was perceived as very useful by clinicians. (21) KI 1 confirmed a positive response to PACK in the Western Cape and reported that it had been rolled out across the province. In the Western Cape province, the monitoring and evaluation of clinical and managerial performance in relation to chronic disease care is achieved through the Integrated Audit for Chronic Disease. The audit has

been implemented across the province and is modelled on the Standard Treatment Guidelines, the Essential Medicines List and the PACK guideline. It includes the monitoring of 5 chronic conditions, namely: Diabetes; Hypertension, Asthma, COPD and Epilepsy and there is a section on patient satisfaction. By 2015, 187 primary health care facilities in the province were participating in the annual audit. According to KI 1, the audit has helped put systems, infrastructure and equipment in place to implement clinical guidelines and improve NCD outcomes. *From audit, I can see there is an improvement. Over the years, I have seen the effort that has been put in, and it is now paying off. It is slow, but it is paying off. (KI 1)* This opinion is borne out by an evaluation conducted by Essel et al. 2015 (23) which showed that in districts where audits had been conducted for a period of time, there were marked improvements in clinical processes compared to districts that had only recently begun doing audits. (23)

2.3. Advocating an integrated approach

Our key informant from the National Department of Health (KI 2) spent much of his interview explaining national efforts to promote a more integrated approach for chronic conditions:

We understand that there are many comorbidities and we cannot continue to just treat diabetes or HIV for example, on its own. If there is specialised care for diabetes, for HIV and all the other common co-morbidities, how many different vertical and parallel services would we have? So, we are moving towards a much more integrated chronic care service. (KI 2)

He did not just refer to medical services:

We would like this service to be as comprehensive as possible and include education and information and assisting with lifestyle change so that patients get more holistic care.... Whilst there are specifics related to each disease, what is common (to the main chronic conditions) is that people need to take their medicine regularly, change their lifestyles and attend support groups. Self-management is extremely important because that means that patients rely on health workers less and come in less often, which give practitioners more time with individual patients. (KI 2)

The provision of specific services for older diabetes patients was not supported by the key informants: *I don't think we should set up different, parallel services for older people with diabetes. In our context, that is not a feasible option.*" (KI 2) It was, however, argued that the move towards integration of care would be of particular benefit to the older patient, *"the older one gets, the more chronic problems one is going to get and if you are going to be coming to see different practitioners on different days, your ability to control your health*

is going to get worse. You will need transport money each time and wait in more queues. That is going to put more stress on you and your family. So yes, the integrated model works extremely well for older people. I think it is a real bonus for them. (KI 2).

2.4. Community-based services

National policy fully endorses the role of NGOs in providing community-based health promotion and patient support: *Around the prevention and early detection of NCDs and the running of support groups, I have absolutely no doubt that the state needs to work hand in glove with NGOs. (KI 2)*

A further component of the national NCD policy is the Central Chronic Medicine Dispensing and Distribution (CCMDD) programme, which aims to more efficiently dispense medicines to chronic patients at external, convenient pick-up points, such as community venues and private pharmacies. (24) Where this is working efficiently, the programme has shown to reduce the need for stable HIV, hypertension and diabetes patients to visit public PHC clinics on a monthly basis to collect their medicines, with the positive effect of decongesting the clinics and reducing waiting times. (24)

In summing up the advantages of the integrated care policy, KI 2 said, *by integrating the treatment of common chronic conditions and building self-assistance into our system by getting people to collect their medication and participate in self-management programmes, the fewer assessments patients will need. That should give the practitioner more quality time with each patient and more time for health promotion activities...that is the model we are aiming for. (KI 2).*

2.5 Implementation of national policy

While the (CCMDD) programme has been initiated in most provinces, it is not clear to what extent other aspects of the policy to integrate chronic care have been implemented. (24) As KI 2 explained, the actual application of the national policy depends on the political will and ability of the provincial departments and the district structures to comply. As a result, there is significant variation in implementation across the nine provinces. There has been some resistance to the change in approach, but this has diminished over time, and where the policy has been implemented, reports are that it has decreased waiting times and increased patient satisfaction. KI 2 reported that: *We've still got some people arguing that diabetes, HIV or mental health are too different... that the one is more important or complex to treat, but once you put them together and people do this for a while, it seems*

to work. We are getting less complaints now. So, we (the national department) are quite happy with the direction things are taking. (KI 2)

3. Theme three: The current model for diabetes care in the Western Cape province

3.1. Facility-level

According to KI 1, who was an official in the Western Cape Department of Health with responsibility for policy implementation on chronic disease and geriatric care, the Department is working towards the implementation of the national policy to integrate chronic care. At the district level, the department has established multidisciplinary Chronic Disease Management teams, which are led by family physicians and include medical officers, clinical nurse practitioners, pharmacists, social workers and rehabilitation staff. The other key informants confirmed that this team has the primary responsibility for diabetes care at the primary care clinic. In each larger geographical service area, there is an Area Committee, which is a large forum with representatives from all levels of the healthcare service. Within those forums, there are different working groups, including one working on the integration of chronic disease care at a primary care level.

There has been lots of consultation. People are buying into this new policy direction. We have a new policy called the Integrated Management of Chronic Conditions (IMCC), which covers chronic communicable and non-communicable disease, as well as mental health...

The policy commits to a whole of society approach to address social determinants and a systems approach to drive the reorientation of the health system to more effectively address NCDs. At the level of the health service, the following components are specified: the delivery of a comprehensive, integrated package of care using a life course approach; good clinical governance and the provision of person-centered, self-management support. Central to achieving the goal of improved NCD outcomes is a productive interaction between a well prepared and proactive provider and a well-informed, empowered patient.

3.1.1. Diabetes Lifestyle Education Collaboration and Action (D-LECA) programme

In line with this policy, the Diabetes Lifestyle Education Collaboration and Action (D-LECA) programme is being adapted to include other chronic conditions. D-LECA is currently being piloted in three community health centres in the metro district as a structured educational and self-management programme for newly diagnosed diabetic patients.

According to the family physician interviewed, everyone in the multi-disciplinary chronic care team plays their part in assisting diabetes patients with self-management. Planning is underway for a phased, scale-up of the adapted version of D-LECA to all facilities in the province. The intention is to combine the resources used in D-LECA and the HIV - ART programme to form a new, holistic and comprehensive self-management programme for chronic conditions. This would move away from a narrow focus on adherence, to empowering patients for self-care and lifestyle change: *D-LECA is about empowering people to get ready to self-manage. The bottom line is, we obviously want people to maintain good health. (KI 1).* A tender has been won by to the Department of Family Medicine and Primary care at the University of Stellenbosch to train a group of master trainers in patient-centered, brief behaviour changes counselling. The plan is to upscale the HIV lay counsellors who already work in primary care facilities so that they can undertake education and counselling for a range of chronic conditions, principally diabetes, hypertension, COPD and HIV. Other categories of health workers will also receive this training.

3.1.2. The Chronic Disease Clubs.

In response to the question regarding which of diabetes self-management programmes or services are already in place in the province, all key informants mentioned the Chronic Disease Clubs. Whilst the stated aim of these clubs is to equip diabetic patients with the knowledge and skills to manage their diabetes, it was clear that currently, they focus mainly on adherence (as with the HIV clubs). The clubs can be either facility based, or community-based and are geared to provide stable chronic disease patients with opportunities to access their medication and have their blood pressure and glucose monitored monthly. Some of them may offer limited health education. As with D-LECA, the Department's intention is to broaden the scope of these clubs so that they offer support for the management of both communicable and non-communicable chronic disease. According to the family physician, these clubs are not working optimally at present: *They are not sufficiently effective. Whilst the nurses are respectful (towards the patients), they just want to get through the queue. Patients are also often keen to get home as soon as possible. Also, patients respect information from doctors more.* She suggested that for the clubs to become more effective, *“the nurses need ongoing training and help from lay workers. A specific doctor should also be allocated to a group and be used as a resource. The priority is to allow for sufficient time for staff to listen to patients – to their questions, experiences and concerns (KI 3).*

She added that the clubs should be fora for patients to share ideas on how to problem solve around common barriers as well as providing for activities, such as cooking demonstrations; exercise classes and fruit and vegetable co-operatives. She further suggested that positive role models and dieticians be invited periodically to give talks and distribute resources. The clinic manager thought it was essential that more staff received in-depth training in diabetes to be able to run these clubs more effectively as a means of promoting diabetes self-management. The health promoter's view was that lay health workers should play a more prominent role in counselling in both the clubs and the clinics *as they can help the healthcare providers get to know the challenges that these clients are facing. They consider the patient's cultural background, their beliefs and values and help with language and cultural barriers. This makes the patients feel more comfortable.* (KI 5) She added that she thought there should be greater community involvement in the running of the diabetes clubs or groups and that the Department should aim to establish clubs in every local community.

3.2. Community-Based Services (CBS)

At the community level, the provincial Departments of Health have outsourced a package of services for chronic disease patients to non-government organisations (NGOs). These NGOs are paid to render a service to a specific community. The NGO pays and manages its own staff, but the Department works closely with them and plays an oversight role. A CBS coordinator, who is a nurse employed by DOH, liaises with the NGOs and Social Service sites run by the Department of Social Development in her area and reports to the CBS programme manager working in the DOH district management structure.

The package of services delivered by NGOs in the Western Cape province varies (as is the case in other provinces too): *It could be just providing medication, which has been pre-packaged by the Chronic Dispensing Units. On a monthly basis, patients will go to a group at a hall, a library or Service Site and fetch their medication. The NGO comes to fetch*

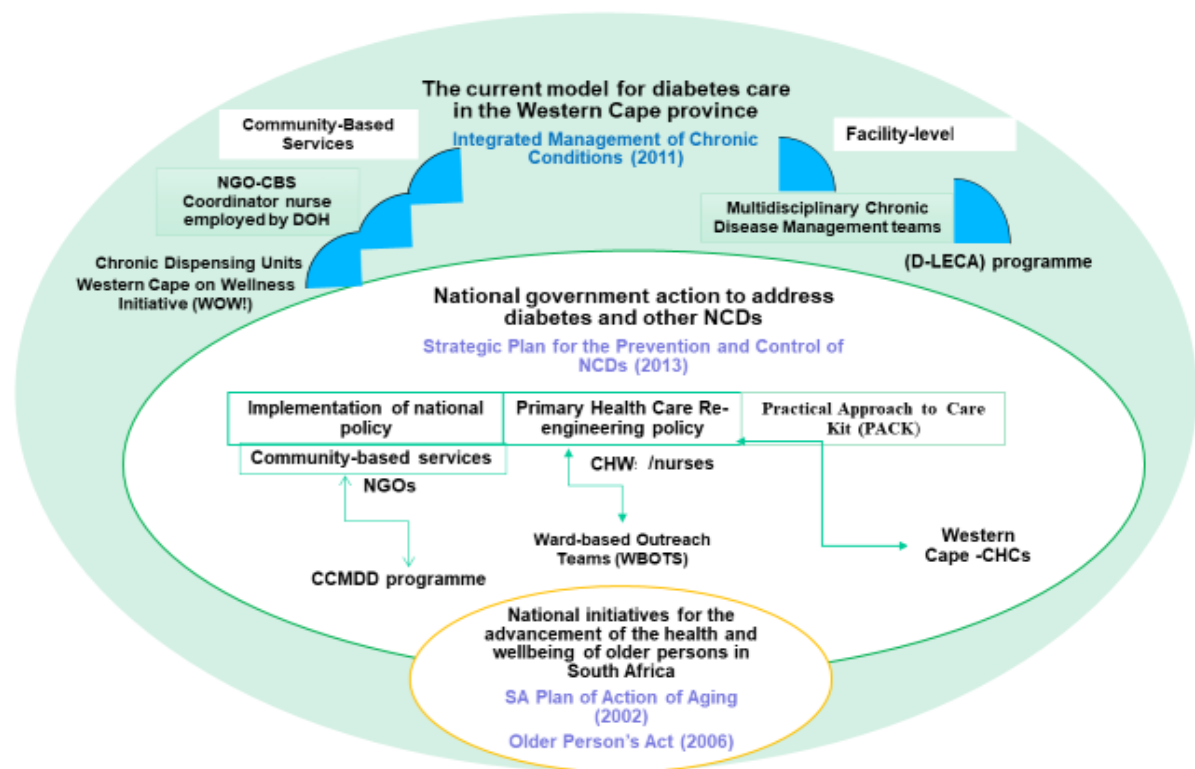


Figure 7-1: summarises all main themes (from the doc review and the KI interviews).

medication from the facility. There are tight control measures in place to ensure the medicines are kept under certain conditions and patients sign for their medication. The nurses oversee this process, and Community Health Workers (CHWs) deliver the service. Or patients could also, in addition, receive education on healthy lifestyle and medication. These groups have different names: they might be called a Self-Management Group or an Empowerment Group or a Wellness Group. (KI 1).

However, again, the Department intends to expand the scope of the work done by the CHWs, the idea is for CHWs to do medication, as well as primary and secondary NCD prevention work in the community. CHWs currently working with HIV patients need to be upscaled to become general counsellors for chronic disease, just like the counsellors at the facility level. But now, we are not quite there (KI 1). The Western Cape Department of Health has also initiated the Western Cape on Wellness Initiative (WOW!) to prevent and reduce the risk of NCDs by promoting physical activity and a healthy diet in the community. Among its activities are training people to establish food gardens; convening a variety of popular physical activities in public spaces and health promotion media campaigns. Figure 7-1: summarises all main themes (from the doc review and the KI interviews).

4. Theme four: Self-management of diabetes among older patients

4.1. Specific programmes for older patients

Within the primary health services in the Western Cape, there are no programmes which address the specific needs of older diabetes patients. KI 1 stated that *older people are not addressed as a separate group. For me the only problem for older people is just the waiting times at the facility We do have an approach that older people and people with disabilities must be taken out of the queue and helped, but it does not always happen like that. It is the responsibility of the staff at the facility to see whether they can reduce the waiting times for older people. (KI 1)*. Fast-tracking older people in queues was confirmed as recommended practice by KI 2.

4.2. Department of Health-Social Services partnership

KI 1 also mentioned that the Department of Health partners with the Department of Social Development to run community-based groups for older people. *The Department of Social Development have groups for older people called Service Sites, where older people still living at home go to socialise and others which are run at old age homes. These are usually run by NGOs paid by Social Development. We have combined forces with them so that we can start providing medication and lifestyle education to chronic patients through NGOs at those sites. In that way, we can avoid starting another group. Social Development has also organised the Golden Games to help older people stay fit and active. There are heats throughout the year and then one big competition a year. (KI 1)*.

4.3. Barriers to effective self-management for older persons

There was consensus among KIs that generally older patients wanted to be compliant, but they faced numerous barriers in managing their condition. *Many of them are hardly managing themselves: they are very dependent on their families in terms of preparing their meals, taking medication and attending follow up appointments. (KI 5)*. For clinicians, the most pressing issue was the lack of time for consultation with chronic patients, especially with those suffering from multi-morbidities. The family physician emphasised that currently, patients are given information in a didactic fashion with little consideration of their individual situation or daily lived experience. *Clinicians need to take time to listen to the patient. If the doctor does not understand the patient's concerns or experiences, then the advice may be inappropriate. You also need time to go through the meds, so they understand the rationale and there needs to be shared decision-making so that there is*

agreement on what meds the patient is willing to take and what can be stopped. (KI 3.) To enhance her own capacity to manage older diabetes patients, she stressed that what she needed most was more time to develop a personal relationship with the patient and their family and to be able to offer greater continuity of care. The health promoter argued that community health workers should be relied on to assist with self-management as they can spend more time getting to understand the patient's context and capacity: *Patients would get more involved (in self-management) if they were in a partnership (with a healthcare provider), where they had time to ask questions and where their cultural backgrounds, values and beliefs were understood. (KI 5).* He was worried that there was currently a shortage of staff to run self-management programmes and implored the Department to employ more diabetes educators.

Further barriers to self-management commonly experienced by older patients are listed in supplementary Table 2 (study4). The key informants also offered their ideas as to how these barriers could be overcome (Figure 7-2).

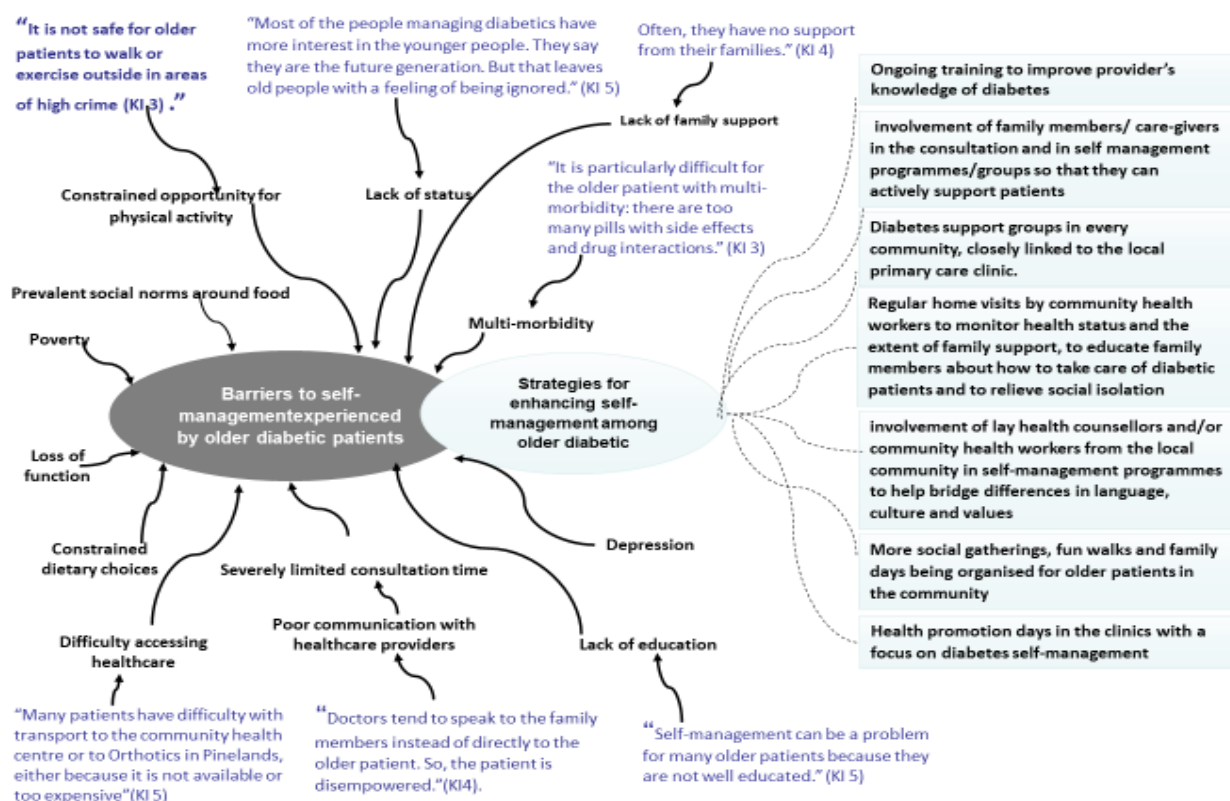


Figure 7–2 Barriers to effective self-management for older persons: the views of key informants.

7.6. DISCUSSION

The epidemiological transition in SA from acute, communicable disease to the prominence of chronic NCDs in an ageing population is resulting in an increased demand for long-term health care, institutional and family support. (23) This situation is recognised by policy makers, managers and practitioners alike and there are multiple efforts both nationally and provincially to re-orientate the healthcare system to focus more effectively on NCDs. This is evidenced by the re-engineering of primary care, which aims to provide integrated services for common chronic conditions; enhance the skills of healthcare practitioners to manage chronic conditions and multi-morbidity; improve access to medicine through the CCMDD programme; strengthen self- management and form strong linkages with communities through NGOs and CHWs, to fill a critical gap in support services that are not provided by organised health care. It was clear from the key informant interviews that, whilst the re-organisation of primary care in this way may not be fully established, it is currently underway at least in the Western Cape province.

The policymakers interviewed made it clear that it is highly unlikely that they would consider introducing a specific programme for older diabetes patients. However, this group does stand to benefit from many of the interventions being implemented as part of the NCD Strategic Plan. As multimorbidity is a consistent feature of NCDs among the older individuals, the integration and coordination of chronic care services is indicated. (25)

The establishment of community-based services to provide self-management support, promote health and ease access to medicine, as well as providing home visits by district-based CHWs helps overcome many of the barriers to care experienced by older patients. It enables services to be delivered early and close to home, decreases waiting times, reduces transport and other associated costs for individuals and provides for continuity of care. (19) For the health system, gains include cost saving with disease averted by health promotion and early detection, reduced facility visits and less overcrowding, making more time available for individual consultations. (19) As our one key informant stated, this would make it more feasible for practitioners to interact with patients and play a more active role in enhancing health literacy, health promotion and self-management. What was not mentioned by the key informants, but which may be of equal importance is that practitioners gain appropriate communication skills and educational resources to effectively educate and counsel patients on lifestyle behaviour change and self-care. These factors have been reported by patients and healthcare providers alike to be

significant sources of frustration and to have a negative impact on the quality of NCD care. (26–28)

To cater to a growing population of older people, the healthcare system also needs to be made more-aged friendly, particularly at the primary care level. According to Samson, many healthcare workers have negative attitudes towards older people and as a result, manageable health issues are overlooked or attributed to the ageing process, resulting in low levels of functioning, poorer health outcomes and diminished quality of life. (29)

The available research on the question of how to improve the care of older patients with diabetes, highlights several important considerations. Poor health literacy related to low educational attainment and limited access to media among older patients is a known contributing factor to suboptimal diabetes outcomes among this group. (30) Older patients may therefore require additional time for health education and self-management support, which is tailored to their cognitive and functional status (older patients with multiple co-morbidities are especially likely to become confused about their treatment). For example, a 2015 survey of diabetes patients >60 years attending public sector primary health care clinics in Cape Town, found very poor knowledge of diabetes complications, its causes and self-management practices. (31) This was both indicative of their low levels of formal education (67% had less than 5 years of schooling) and the extremely limited time and resources health care providers had to educate and counsel diabetic patients. (31) It has been argued that since older patients need more time for communication with providers, health services should be more responsive to and centred on their needs and that support needs to be provided in the community from healthcare workers who understand the local context and language. (32) Community-based support groups run by lay health workers have been shown to be particularly helpful in providing such extended support for older people. For example, Gilden et al (1992) (33) reported that older diabetic patients who attended a series of educational and social support groups had better knowledge, greater family involvement and improved quality of life; experienced less depression and stress and achieved greater glycemic control than a control group. It is also recommended that there be greater recognition of and support for the important role of the family and non-professional caregivers in keeping older patients functionally independent and at home, thereby reducing health and social care costs (34). They should be included in support groups and consultations with healthcare providers, where the older patient's ability to self-manage is frequently reviewed. (34) Older patients have been found to be at high risk of nutritional deficiency, with undernutrition and over-nutrition, as well as food insecurity. (35)

This suggest that nutritional status and the risk of hypoglycaemia should be included in such reviews. (33) As a group, older diabetic patients are also at higher risk of untreated depression and/or anxiety, indicating that greater attention be afforded to the screening and treatment of mental health among older patients with diabetes. (36)

7.7. Conclusion

Whilst there have been some significant policy interventions pertaining to the protection of the health and welfare of older persons in SA, the needs of this vulnerable group remain relatively low on the list of priorities in terms of focus and resource allocation. In this context, older people, as a distinct group, are also not a strong focus in current health policy relating to the provision of NCD care. However, the various initiatives currently underway to re-engineer the healthcare system in SA to more effectively deal with NCDs, will go some way to meeting the identified needs of older diabetic patients and to addressing their barriers to care. However, as part of this re-modelling exercise, it is perhaps opportune for the health department to consult older chronic care patients and involve them in decision making and the planning of services. This paper alerts policymakers and clinicians to some of the specific issues considered to be pertinent and important in the care and management of older diabetic patients. Many of these would also be applicable to older patients with other chronic conditions.

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Competing interests

The authors declare that they have no financial or personal relationships which may have inappropriately influenced them in writing this paper.

Authors' contributions

MW was PhD student. NSL and KS were the supervisors. MW and KM collected and analysed the data. MW wrote the initial manuscript. KM, NSL and KS reviewed and edited the manuscript.

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Chapter 8

Study 5: The effectiveness of peer and community health worker-led self-management support programs for improving diabetes health-related outcomes in adults in low-and-middle-income countries: A systematic review

Role of the candidate

I was responsible for designing the protocol review of the study. I did the literature search selected the studies, evaluated risk of bias and extracted the relevant information independently with Ms. Cecilia Hoegfeldt (CH), Professor Peter J Raubenheimer (PR) and Dr Mark Engel (ME). I have managed and cleaning the data and preparing it for analysis I carried out the analyses, supported by Professor Dinky Levitt (NSL). I drafted the manuscript, incorporating input from co-authors and I was responsible for finalising the final version of the manuscript for publication.

Role of the co-authors

AM, MEE, APK, NSL CH, NP SK conceived the study and were contributed in designing the protocol and provided critical guidance on the analysis and overall direction of the study. All co-authors critically revised successive drafts of the paper and approved the final version.

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4513536/>.

8.1. Abstract

Objective: Community-based peer and community health worker-led diabetes self-management programs (COMP-DSMP) can benefit diabetes care, but the supporting evidence has been inadequately assessed. This systematic review explores the nature of COMP-DSMP in low and middle-income countries' (LMIC) primary care settings and evaluates implementation strategies and diabetes-related health outcomes.

Methods: We searched the Cochrane Library, PubMed-MEDLINE, SCOPUS, CINAHL PsycINFO Database, International Clinical Trials Registry Platform, Clinical trials.gov, Pan African Clinical Trials Registry (PACTR) and HINARI (Health InterNetwork Access to Research Initiative) for studies that evaluated a COMP-DSMP in adults with either type 1 or type 2 diabetes in World Bank-defined LMIC from January 2000 to December 2017. Randomised and non-randomised controlled trials with at least three months follow up and reporting on a behavioural, a primary psychological, and/or a clinical outcome were included. Implementation strategies were analysed using the standardised implementation framework by Proctor et al. Heterogeneity in study designs, outcomes, the scale of measurements, and measurement times precluded meta-analysis; thus, a narrative description of studies is provided.

Results: Of the 803 records identified, ten studies with 5008 participants were included. COMP-DSMPs were inconsistently associated with improvements in clinical, behavioural and psychological outcomes. Many of the included studies were evaluated as being of low quality, most had a substantial risk of bias and there was significant heterogeneity of the intervention characteristics (for example, peer definition, selection, recruitment, training and type, dose and duration of delivered intervention), such that generalization was not possible.

Conclusions: The evidence supporting the use of COMP-DSMP for people with diabetes in LMIC is equivocal. Well-designed and implemented trials are urgently needed to determine whether such programs should form an integral part of diabetes care strategies, which necessitates better funding and training of researchers.

Registration: This review registered with the International Prospective Register of Systematic Reviews [registration number CRD42014007531].

Keywords: Systematic review, peer support, non-professional community health worker, diabetes self-management support, low-and-middle-income countries

8. 2. Introduction

Over the past decade, diabetes prevalence has risen faster in low- and middle-income countries (LMIC) than in high-income countries (HIC). (1) Currently, about 80% of people with diabetes worldwide live in LMIC and projections suggest that some of these countries will experience more than a twofold increase in the number of people affected over the next 20 years.(1) People living with diabetes need not only medical treatment from their health care providers; equally important is self-management and sustaining complex self-care behaviours. These behaviours (under the umbrella of “self-management”) include following complicated medication regimens and often embarking on significant lifestyle changes in diet and exercise programs, monitoring and responding to symptoms, and coping effectively with stress. (2-4)

Evaluation of diabetes self-management programs has shown improved health outcomes and reduced utilisation of health services. (5–7) However, without continuous support, many adults will not succeed in managing their condition well, leading to worse health outcomes, including expensive hospitalisations and avoidable complications, (8) It is critical for health care providers and the settings where they work to have the resources and a systematic referral process to ensure that patients with diabetes consistently receive both diabetes self-management education (DSME) and diabetes self-management support (DSMS). DSME is defined as the ongoing procedure of facilitating the knowledge, skill, and ability necessary for diabetes self-care, while DSMS is defined as activities assisting the diabetic patient in implementing and sustaining the behaviours needed to manage his/her condition on an ongoing basis beyond or outside of formal self-management training. The type of support provided can be behavioural, educational, psychosocial, or clinical (9). The initial DSME is typically provided by a healthcare professional, whereas ongoing support can be provided by personnel without a formal health tertiary education (9). However, health resources, infrastructure, and well-equipped health staff are often limited in LMIC which complicate the delivery and sustainability of DSME and DSMS.(10)

A potential solution for delivering diabetes self-management support could be task-shifting. This is the process whereby tasks are moved, where appropriate, to less specialised health workers and is thus expected to reduce health care expenses while improving health care coverage. (11) Lay health workers from the community such as ‘patient-peers’ or community health workers (CHW) are ideally suited for such task-shifting since existing research suggests that such programs are an effective and relatively inexpensive means to help patients manage chronic

conditions. (12, 13) Furthermore, these programs have been recommended by the World Health Organization review committee on peer support in diabetes as a resourceful way for diabetes management. (14)

Existing COMP-DSMPs involve two types of closely related lay health care workers; 'patient-peers' (here called 'peers') and community health workers (CHW). For the purpose of this review, Dennis's (15) comprehensive definition of peer support, as used in a recent Cochrane review, (16) is employed. Dennis defines peer support as "provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population, to address a health-related issue of a potentially or stressed focal person". (15) To possess this experiential knowledge, peers must be affected by the same condition as the patient population they serve. In the context of diabetes, peers often have diabetes themselves or have a family member with diabetes. Their support can help metabolic control by sharing, discussing, identifying, and facilitating behaviours, which can improve diabetes self-management and overcome obstacles to care and self-care. (17)

CHWs constitute another form of lay health workers based in the local community. WHO defines CHWs as health workers without a tertiary education health certificate, who are members of the communities where they work and are supported by the health system, although not necessarily part of its organisation. (18) In contrast to peers, CHWs does not necessarily have the experiential knowledge of being a patient. Yet, similar to peers, CHWs speak the language and share culture and community with the patients with whom they work. Like peer-support, CHW-support varies widely across different contexts and may include both self-management support as well as direct patient care. (19, 20) Furthermore, both CHW and peer-support interventions (here collectively referred to as COMP-DSMPs) differ in the extent and type of formal training that peers/CHWs receive; in whether peers/CHW are paid members of a healthcare team or volunteers; in the type and extent of time commitment required of the peers/CHW; and in the principal method of peer support (for example, face-to-face contact versus telephone contact) .(21)

A considerable body of evidence from well-designed RCTs, mainly in HIC, demonstrate improved clinical and behavioural outcomes such as glycaemic control in diabetes populations receiving peer/CHWs support (22–31) This is further supported by several systematic reviews. A systematic review conducted by Zhang et al. (32) suggested that home-visit-intervention and curriculum-combined-reinforcement-intervention performed by peers had a better effect on improving glycaemic control compared to conventional care . Furthermore, a systematic review

by Norris et al. reported positive changes in lifestyle and self-care in some studies of CHW-led interventions for diabetes self-management. Although limited data on economic outcomes is available, several studies demonstrated a reduction in health care expenses as a result of the CHW-led intervention (33).

At present, there are no systematic reviews of peer/CHW support programs for diabetes focusing on LMICs. Furthermore, most systematic reviews to date have not applied a standardised framework for analysing and evaluating the implementation strategies across studies. Systematic categorisation and assessment of implementation outcomes are critical for assessing whether an implementation strategy has been applied successfully since an intervention will not be successful unless both the implementation of the strategy in a given context *and* the components of the strategy itself are effective. (34) In the case of failure, it is essential to know if this was due to the intervention being ineffective in the new setting (intervention failure), or if an intervention was deployed incorrectly (implementation failure). (35) To bridge this gap in the existing literature, this systematic review aims to employ a standardised taxonomy for analysing and evaluating COMP-DSMPs implementation strategies in LMIC for diabetes self-management. We strive to answer the following questions: What are the effects of COMP-DSMPs on the clinical and behavioural outcomes of adults with diabetes, and how consistent are those effects across existing studies? What were the program designs used and how were the implementation outcomes assessed?

8.3. METHODS

A full study protocol was developed and published in a peer-reviewed journal. (36) The systematic review has been slightly modified from the protocol. Firstly, a meta-analysis was precluded by the quality of the included studies. Secondly, the research question addressing 'how COM-DSMP can help improving quality of diabetes care' has been modified to addressing 'the program designs used, and the implementation outcomes assessed' since there was insufficient information on the quality of care in the included studies. Finally, implementation taxonomy frameworks by Proctor et al. (40) have been adopted for analysis and evaluation of the implementation strategies. This review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (37) and is registered with the International Prospective Register of Systematic Reviews [registration number CRD42014007531].

8.3.1. Search strategy

We searched the Cochrane Library, MEDLINE via PubMed, SCOPUS, CINAHL, PsycINFO, and Web of Science databases for studies published between 1 January 2000 and 31 December 2017, which evaluated COMP-DSMPs in adults with diabetes in LMIC. Drawing on a combination of

free-text search terms, Medical Subject Headings and database-specific subject headings, we developed a sensitive search strategy for multiple electronic databases (Additional file 1), combining synonyms for 'diabetes', 'peer support', 'community health worker', 'intervention' and 'LMIC'.

Other database resources such as Google Scholar, WHO, Peer for Progress, International Clinical Trials Registry Platform, Clinicaltrials.gov, Pan African Clinical Trials Registry (PACTR) and HINARI (Health InterNetwork Access to Research Initiative) for LMIC were searched (Additional File 1). We similarly explored the reference lists of key articles and journals.

8.3.2. Selection of studies.

Titles and/or abstracts of studies were identified using the search strategy, and those from additional sources were screened independently by two reviewers (MW, PR). They individually assessed the eligibility of the articles first based on the title and abstract and later on full-text. Any disagreement between the two reviewers was resolved through discussion with a third author (NSL) on the study team.

Inclusion criteria

- **Types of studies:** Studies that measured the effects of COMP-DSMPs in randomised controlled trials (RCTs), non-randomised controlled trials and quasi-randomised controlled trials were included. The quasi-randomised controlled trials included controlled studies with a comparison group and uncontrolled studies with 'before and after' study designs. We included both controlled and non-controlled before and after studies because they are accepted research designs for improvement strategies and are widely used, especially so in LMIC where the resources are not available to conduct RCTs, (38)
- **Types of participants/population:** Only studies from LMIC based on the World Bank classification of country income groups were included. (39) Study participants had to be ≥18 years of age and have either type 1 or type 2 diabetes, but not gestational diabetes nor diabetes due to other causes. We included type 1 and type 2 diabetes because several studies from LMIC do not differentiate between these two diagnoses.
- **Types of interventions:** Studies that reported contact with an individual or a group of peers (paid or voluntary) offering COMP-DSMP with a minimum follow-up period of three months were included. Peers could be CHW, peer leader, lay health advisor, lay health educators, or peer coaches. Peer support that was exclusively telephone- and web-based were excluded. Interventions led or facilitated by a professional (or non-peer) were

included, providing that the focus of the intervention was to provide peer-to-peer interaction. Studies in which peer support was part of a multicomponent/complex intervention, where the effects of the peer support element could not be isolated, were excluded.

- **Types of control/comparator groups:** Studies, in which the control/comparator group received usual care or professional health worker-led diabetes self-management support (and not peer-support) with a follow-up period of three months or more were included.
- **Types of outcomes:** Studies that reported at least one of the following outcomes were included. *Behavioural* – such as physical activity/fitness, glucose monitoring, adherence to medication, improved nutrition, and self-care. *Psychological* – such as self-efficacy, knowledge, attitudes, quality of life, confidence, self-esteem, well-being, vitality, social functioning, coping, as assessed by validated measures. *Clinical* – such as fasting and random blood sugar levels, glycated haemoglobin (HbA1c), cholesterol, blood pressure, body mass index (BMI), symptoms of hypoglycaemia and hyperglycaemia, and hospitalisations or clinical visits.
- **Language:** Restricted to English
- **Time restriction:** We decided to restrict the search to the period following the changes to the diabetes diagnostic criteria in 1999 based on the WHO Expert Committee on Diagnosis and Classification of Diabetes. Thus, all studies from January 2000 to December 2017 were eligible if the other inclusion criteria were met.

8.3.3. Assessment of risk of bias of studies

Four reviewers (MW, PR, NP, and KB) independently evaluated and reported on the risk of bias as described in the Cochrane Handbook for Systematic Reviews of Interventions according to the criteria and associated categorisations contained therein (Additional File 2), (38) A consensus was reached after discussion and consultation with another reviewer (ME). The detailed reporting included the following variables: Sequence generation, allocation concealment, blinding (participants, providers, outcome assessors and data analysts), completeness of outcome data and selective reporting (38) (Additional File 3).

8.3.4. Data extraction and synthesis

The following data were extracted independently by three reviewers (MW, PR and NP): author, year of publication, geographic region, study design, description of the intervention (including process, cost of programme, cost-effectiveness if available, context of intervention (i.e., primary

health facility), details about group leader (demographics, training, professional status, etc.), details about participants (including number of each group, baseline health information, demographic characteristics), length of intervention and follow-up, definition of peer used and health outcomes. The data abstraction forms based on the Cochrane Consumers and Communication Review Group's Data Extraction Template for Cochrane Reviews were modified to fit this review. A consensus was reached by discussion and consultation with other reviewers (ME, NSL) where necessary.

8.4. Taxonomy for analysing implementation strategies:

The taxonomy used to investigate and evaluate the implementation strategy of each study is based on previously published conceptual frameworks by Proctor et al. (40-42) Proctor et al. (40) propose guidelines for naming, defining, and operationalising implementation strategies in terms of seven dimensions; actor, the action, action targets, temporality, dose, implementation outcomes addressed, and theoretical justification. For this review we categorised and analysed the included studies by applying six of the proposed dimensions (table 2), whilst 'implementation outcomes addressed' are separately analysed by the taxonomy proposed by Proctor et al. (42) (Table 3). Although the conceptual framework is intended for researchers planning implementation strategies, it allows for systematic investigation, evaluation and comparison of the nature of the implementation strategies in the included studies. Furthermore, it enables investigation of whether the studies suffer from commonly reported problems in current implementation research such as inconsistent labelling, poor descriptions, and unclear justification for specific implementation strategies. *The actors* are defined as the stakeholder delivering the strategy; *the actions* are defined as those actions enacted by the actors; *action targets* are the population *targeted* by the intervention and how the actions are supposed to impact this population; *temporality* is defined as the phased nature of implementation meaning at which stage was the strategy used relative to other stages; *dose* is defined as the frequency and intensity of the implementation strategy such as the amount of time spent with an external facilitator; and *theoretical justification* is defined as the justification or rationale for the implementation strategy, which can be theoretical, empirical, and/or pragmatical.

8.4.1. Taxonomy for evaluating the implementation strategies:

We systematically investigated whether studies reported on the eight implementation outcomes prescribed by Proctor et al (42): *acceptability* (i.e. the perception among stakeholders that an intervention is agreeable), *appropriateness* (i.e. the perceived fit or relevance of the intervention in a setting or for a particular target audience or issue), *feasibility* (i.e. the extent to which an

intervention can be carried out in a specific setting or organisation) , *adoption* (i.e. the intention, initial decision, or action to try to employ a new intervention), *penetration* (i.e. the degree to which the population who is eligible to benefit from an intervention actually receives it), *sustainability* (i.e. the extent to which an intervention is maintained or institutionalised in a given setting), *implementation costs* (i.e. the incremental cost of the delivery strategy), and *implementation fidelity* (i.e. the extent to which an intervention is delivered as planned). We assessed implementation fidelity (IF), using the models of Carroll et al. (43) and Schoenwald et al. (44)

8.5. Statistical analysis.

Comparisons between groups for continuous outcomes were conducted using mean differences (MD) and their corresponding 95% confidence intervals and p-values. For binary outcomes, proportions or percentages were compared using Chi-square tests. Most studies used regression analyses to compare outcomes between the study groups with adjustments for multiple comparisons, baseline, and confounding variables, and in these cases, we used the p-values reported by the study authors. However, differences in study designs, outcomes, the scale of measurements, and measurement times precluded meta-analysis. We, therefore, provide a narrative summary of the findings across studies.

8.6. Results

8.6.1. Summary of the searches

A flow consort diagram of the studies selected for inclusion is summarised in Figure 1. A total of 803 records were identified from searches. After removal of duplicates, title and abstract screening, 238 articles were selected for further evaluation via full text, of these 228 full text articles were excluded; 192 were not from LMIC, 17 did not include patients with diabetes, 6 assessed outcome measures not relevant to the study criteria, 3 were reviews or protocol papers and 2 were co-led by professionals and peers. Thus, only ten studies met the inclusion criteria and were included in the systematic review. These studies were published in the period from 2008-15 based on patient populations in the following countries: South Africa (n=2), Cameroon (n=1), Uganda (n=1), China (n=2), Cambodia (n=1) Argentina (n=1), Guatemala (n=1) and Jamaica (n=1). The included studies comprised three RCTs, (45-47) one non-randomised parallel arms intervention study (48) and six *pretest-posttest* studies. (49-54) The sample sizes in the studies varied from 19 to 2714; in total there were 5008 participants in this review. Seven studies investigated support provided by peers, while the remaining three studies explored support provided by CHWs.

8.6.2. Quality of included studies

The studies included were mostly of low quality. Four studies did not discuss sources of bias or limitations of the study findings, (50, 52, 53, 54) while two others did not provide details on the randomisation techniques. (45, 46) Only one study, less et al., reported rate of lost to follow-up, which was 15%. (54) Performance bias blinding (participants and personnel) was rated as high risk in all studies except Zhong et al., (45) where performance bias blinding was evaluated unclear.

The studies exhibited substantial heterogeneity in study design with only three of the ten included studies being RCTs. The outcomes measured, except for biological variables such as HbA1c, were insufficiently defined and reported for assessment in many of the studies; in many studies, outcomes were self-reported and different instruments and methods were used to record the data. A summary of the risk of bias in selected studies is illustrated in Table 1.

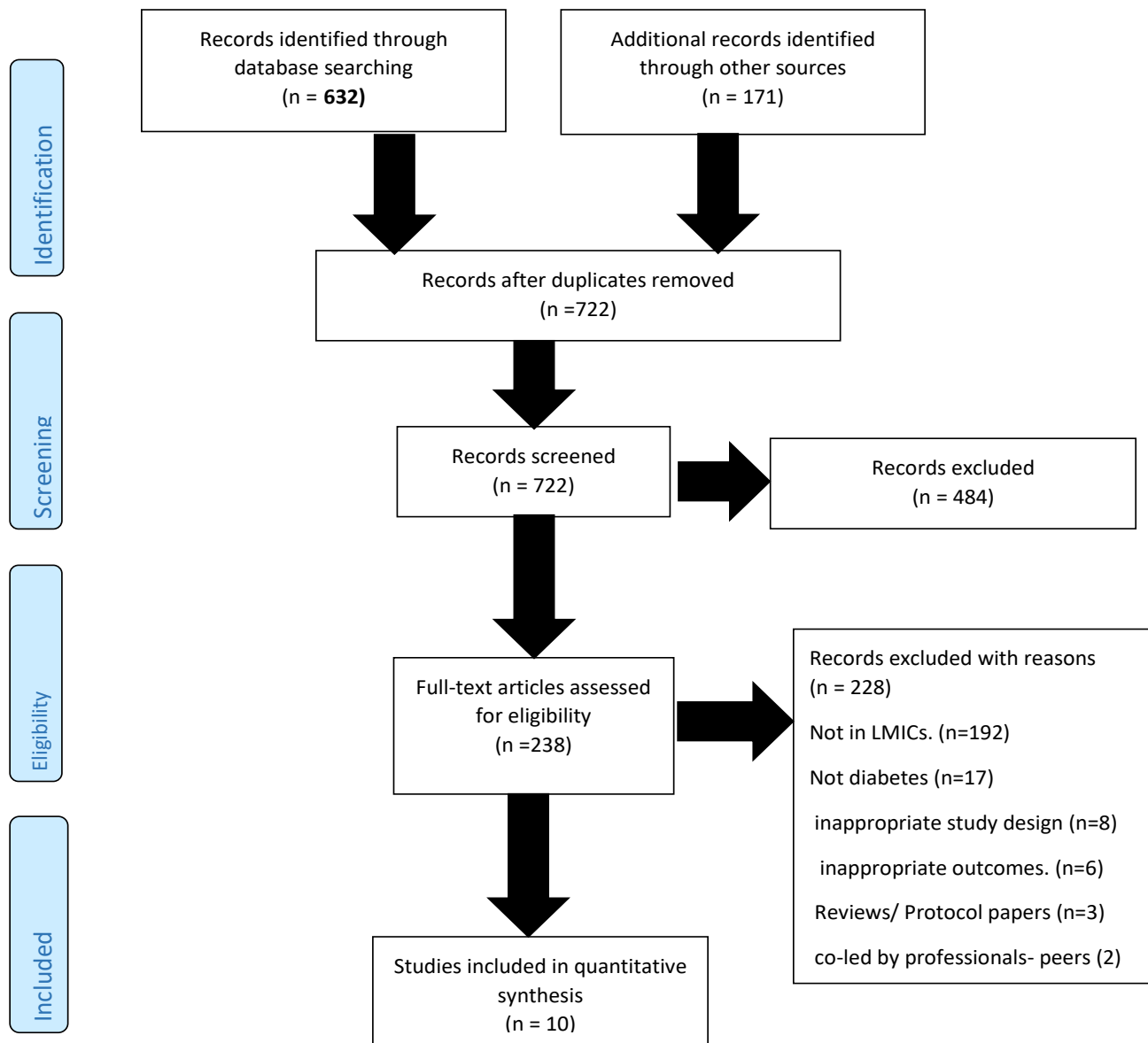


Figure 8–1 The PRISMA Flow Diagram depicting the flow of information through the different phases of the systematic review

Table 8–1 Risk of bias for included studies

<i>Authors -year</i>	<i>Selection bias Random sequence generation</i>	<i>Selection bias (Allocation concealment)</i>	<i>Detection bias Blinding (outcome assessment)</i>	<i>Attrition bias Incomplete outcome data</i>	<i>Reporting bias Selective reporting</i>	<i>Performance bias Blinding (participants and personnel)</i>
Zhong et al., 2015 (45)	NCR	NCR	High	High	Low	NCR
Gargliardino et al, 2014 (46)	NCR	NCR	High	NCR	Low	High
Mash et al., 2014 (47)	Low	NCR	High	Low	Low	High
Assah 2015 (48)	High	High	High	NCR	High	High
Micikas et al., 2014 (49)	High	High	High	NCR	High	High
Baumann et al., 2014 (50)	High	High	High	Low	Low	High
Huixia et al., 2008 (51)	High	High	High	NCR	Low	High
Eggermont et al., 2011 (52)	High	High	High	NCR	Low	High
Rotheram- et al., Borus 2012 (53)	High	High	High	Low	Low	High
Less et al., 2010 (54)	High	High	High	Low	Low	High

NCR: Not clearly risk

8.6.3. Taxonomy of Implementation of peer support strategies.

Table 2 illustrates the taxonomy of the peer/CHW support implementation strategies in the included studies based on the framework by Proctor et al. (40)

Actor – who delivers the strategy?

Across the studies, the actors providing the support varied; in seven studies actors were peers (45,46,48,50-53), while in three studies the support was provided by CHWs. (47,49,54) In the peer-led interventions, peers were often volunteers selected based on their knowledge, experience, and adherence to medication and lifestyle changes (45, 46,48, 52,53) and thus functioned as role models for patients. Only in one study (51), peers were deliberately selected

based on their everyday life challenges being similar to those of the patients, while another study did not describe the skill-level of the peers. (50)

No description of the CHWs in the three included studies was given, other than they were non-professional health workers (i.e. without a formal health tertiary education) from the local community. In all the studies, the peers/CHWs received training prior to commencing the intervention; most training courses lasted a few days. In one study, Eggermont et al. (52) training lasted six weeks. However, in this study, peers also played crucial roles in screening and monitoring clinical measures in patients in addition to providing DSME and DSMS.

Actions – which actions do the actors enact?

Across the studies, the peers/CHW aimed at equipping the patients with knowledge, support and skills to manage their diabetes. Thus, the peers/CHW provided DSMS and DSME. In most of the studies, peers/CHW led the group and discussion meetings, (45,46,48, 49, 52, 53, 54) as well as more informal activities such as organising physical activities and cooking classes. In all studies, peers/CHW provided emotional and/or social support through informal contact with the patient through in-person interactions and/or telephone contact. In two studies emotional and social support formed the basis of the intervention, (50,51) Two studies (50,53) emphasised a deep-grounded one-to-one contact; where peer educators in Baumann et al. (50) were paired with patient peers, peers facilitated the establishment of buddy pairs between patients in Rotheram-Borus et al. (53). In the remaining interventions, the actions by peers/CHWs targeted both groups and individuals depending on the form of activity. In terms of the types of studies, the interventions were group-based in the three RCTs (45-47) and in five of the seven non-RCT studies; the remaining two non-RCTs were one-to-one interventions. (50,54)

Targets of action – Who/what are the actors attempting to impact?

All interventions aimed at enhancing emotional and social support for and improving self-care behaviours and management in adults with diabetes. Furthermore, by improving emotional/social support and self-management, the studies aimed to improve clinical outcomes such as glycaemic control, blood pressure, and BMI. Most of the studies targeted T2DM patients exclusively, while two studies did not distinguish between T1DM and T2DM. (52, 53) In two studies the intervention specifically targeted patients without major comorbidities, (46,45) while the intervention in one study (52) targeted diabetes patients, of whom some also had hypertension. In one study the intervention targeted older adults (60 years and above) exclusively. (51)

Temporality – when does the strategy take place?

In all studies, the actions by the actors (i.e. peers/CHW) were commenced following their own training. Only a single study, Shen (2008), outlined the relative time from completion of peer/CHW training and the commencement of the interventions. (51)

Dose – what is the frequency and intensity of the intervention?

The intervention strategies varied in duration and frequency; the strategies ranged from weekly 40-minute group discussions (46) to weekly teaching sessions (90-120 min each) and group discussions. (51) The follow-up periods varied between 3 months to twenty-four months (three months (51), four months (49,50) and six months, (48,55,54) 12 months (45-47) and 24 months. (53)

Justification – which (theoretical, empirical, pragmatic) justification is provided for the choice of implementation strategy?

Most of the studies justified the utilisation of a peer/CHW based intervention for diabetes by referring to existing literature, which highlights peer/CHW based interventions can contribute to improving chronic conditions. Furthermore, most studies justified the peer/CHW based intervention by referring to studies showing that such interventions provide a low-cost, flexible means to improve care for chronic conditions in resource-constrained health systems. A few studies also conducted formative research including focus groups and individual interviews in the communities to aid the development of interventions. The formative research illustrated that peer/CHW interventions were desired and/or suited for the given communities. (53;51;45;49)

Table 8–2 Taxonomy of implementation of peer support strategies in LMIC by mode of delivery.

<u>Study ID & design</u>	<u>Country</u>	<u>Actors</u> Who delivers the strategy?	<u>Actions</u> Which actions do the actors enact?	<u>Targets of action</u> Who/what are the actors attempting to impact?	<u>Temporality</u> At which phase is the strategy used?	<u>Dose</u> At which frequency and intensity is the strategy used?	<u>Justification</u> Which (theoretical, empirical, pragmatic) justification/rationale is provided for the choice of implementation strategy?
Assah et al., 2015 Non-RCT (45)	Cameroon	Peers – volunteers with diabetes selected based on their compliance with treatment, good glycaemic and metabolic control, and their experience. Received 2-day training workshop.	Actions —actors led group meetings on self-management and conducted personal and telephone-based support.	Targets - actions were aimed at improving self-care behaviours; knowledge; clinical outcomes (glycaemic levels, blood pressure, lipids); providing emotional and social support for adults with poorly controlled T2DM.	N/A	Dose –Group meetings - monthly for 6 months. Personal + telephone encounters - 5 monthly over 6 months.	Justification – Research shows that peer-support care models provide low-cost, flexible means to supplement formal health care support for chronic diseases.
Baumann et al., 2015 Pre-post quasi-experimental study (50)	Uganda	Peers (called champions) – people with diabetes who were able to read and speak English and receive 2 days training in communication, emotional support, and assistance with daily management. Other selection criteria not specified.	Actions – actors were matched with patient peers and provided emotional support and assistance with daily management through facilitating personal and telephone.	Targets – actions were aimed at improving diabetes self-care behaviours, glycaemic control, social support, emotional well-being, and linkage to health-care providers for adults with T2DM.	N/A	Dose – Contact between peers and partners (telephone/in person) - at least once a week over 4 months.	Justification – WHO suggests that peer support is a promising approach toward achieving self-care goals in a developing world setting with shortage of health workers, which is supported empirically.
Eggermont, 2011 Pre/post	Cambodia	Peers – recently recovered from years of serious illness from poor glycaemic	Actions – actors educated and provided skills of self-management; supported adaptation of	Targets – actions aimed to improve health outcomes (blood glucose, blood pressure, BMI), ability to control	N/A.	Dose – Classes – 6 in the home of peer educator.	Justification —Peer support models are theoretically promising for resource constrained health systems and

(52)		control. Received 6 weeks of training.	life-style including nutrition and daily exercise; and mediated contact to professional health staff when needed.	disease, and empower people with diabetes (some also had hypertension).		Monitor glucose levels – twice monthly Time period not specified.	underpins patient-centeredness, supported by some empirical evidence.
Gagliardino et al., 2013 RCT (46)	Argentina	Peers – patients with diabetes recruited on the basis of their excellent diabetes control, self-motivation, communication and support skills. Recruited from an NGO devoted to education of people with diabetes. Received 3-days training in DSM and communication.	Actions —actors implemented a diabetes educational program, provided psychological and behavioural support through phone-calls to patients and face-to-face interviews in small groups.	Targets – The actions aimed at improving and sustaining self-care behaviours and hereby clinical outcomes in adults (25-75yr) with T2DM, who had been followed for at least 2yr by physicians without major co-morbidities.	N/A	Dose – Educational course – 4-week program (4 modules, 90–120min). 1 reinforcement session 6 months after. Calls – weekly for 6 months post-course, biweekly next 3 months, and monthly for last 3 months. Interviews – bimonthly for 1-yr post-course.	Justification –Research shows that diabetes self-management education is effective for improving clinical outcomes and quality of life of people with diabetes, but many organizations are not equipped to manage its implementation. This gap can be bridged by peer programs, supported by research from other chronic conditions.
Rotheram-Borus et al., 2012 Pre/post (53)	South Africa	Peers – volunteers with diabetes who had lost weight and increased exercise after T2DM diagnosis.	Actions – actors a) led psychoeducational group sessions, b) facilitated buddy pairs between women with diabetes in order for these women to support each other's behaviour change via telephone text-communication.	Targets – Actions aimed at enhancing self-management for women with diabetes (1 T1D, rest T2DM) who had suffered diabetes symptoms for more than 5yr. Further, actions aimed to facilitate successful buddy pairs, where women with diabetes would support each other's behaviour change and hereby clinical outcomes.	N/A	Dose – Psychoeducational group sessions/ Informational support meetings – 12 weekly meetings. Text-messages – daily. Time period not specified.	Justification –Research suggests that peer support can bring significant improvements in chronic disease diagnosis and care. Formative research informed the adaption of the 'Power to Prevent Program' to the study setting.

Shen, 2008 Pre/post (51)	China	Peers – older people with T2DM, living in the same community, non-health professionals. They were very similar to general participants.	Actions – actors led a social support and self-efficacy enhancing group activities (SSS-activities). Actors facilitated frequent informal contact and collective peer group meetings.	Targets –Older people with T2D (≥60yr). Actions are targeted at changing self-management behaviours and subsequent improvement of health outcomes by influencing self-efficacy and social support.	Temporality - Informal peer-led SSS-activities started at the same time as basic diabetes information (BDI) by health professionals. Formal SSS-activities 1wk after ended BDI sessions.	Dose – SSS activities lasted 12 weeks. Informal contact- at least once a week. Collective group meetings held fortnightly from 5-12 th week of study.	Justification – Social cognitive theory used as a framework. Research shows that peer education can be used in health promotion and disease prevention programs to lower costs of health education programs. Formative research provided the basis for development of a peer-led T2D self-management program.
Zhong et al., 2015 RCT (45)	China	Peers – volunteers, who were retired adults diagnosed with diabetes for a mean of 9.3yr, had received training for 3 days in basic skills and DSM. Generally adhered to medication and behavioural management regimens.	Actions – actors led educational meetings on DSM, discussion meetings, and organized informal health promotion and support activities such as physical activities.	Targets – Actions aimed at assisting and encouraging daily diabetes management; providing ongoing social and emotional support; linking community resources and primary care for adults (>15yr) with T2DM without major co-morbidities.	N/A	Dose – Educational meetings – 12 bi-weekly over 6 months. 1.5-2h Discussion groups – 12 bi-weekly over 6 months Informal activities – not specified.	Justification – Research suggests that peer support can improve diabetes management. Furthermore, a formative evaluation conducted prior to the study indicated substantial support for the peer-led support program.
Less et al., 2010 Pre/post (54)	Jamaica	CHW – community health workers classified as local people who were not expected to move away from their communities. Received training and had to complete a standardized questionnaire/test.	Actions – actors provided education in DSM through group and one-to-one sessions either at the clinic or in the patients' homes, when patients could not come to clinic.	Targets – Actions aimed at increasing knowledge and improve control amongst T2DM patients.	N/A	Dose – Group sessions and one-to-one interactions – frequency not specified, lasted 6 months.	Justification – Due to high net migration rates, training and retaining diabetes educators as part of primary health care system is not feasible. Peer- or lay educators may bridge this gap.

Mash et al., 2014 RCT (47)	South Africa	CHW (Health promoters) – lay people employed by community health centres. They were trained (6-day workshop).	Actions –actor-led sessions of group diabetes education using a guiding style of communication and provided counselling.	Targets – Actions aimed at enhancing self-management and thus health outcomes for adults with T2DM.	N/A	60min monthly sessions over 4 months.	Justification – Poor and limited health infrastructure in LMIC requires task-shifting to cope with the burden of diabetes.
Micikas et al., 2015 Pre/post (49)	Guatemala	CHW – nature of these not specified. The actors were selected from a group of community health workers based on interviews. The selected CHW received further training.	Actions – actors led education (diabetes club meetings including self-management education, emotional support, physical activities); advocacy (home visits including emotional and medication support); and pre-consults in the clinics with nurse.	Targets – Actions aimed at improving education, support, and ultimately the health and quality of life of T2DM patients.	N/A	Club Meetings – weekly Home-visits – weekly Pre-consults – monthly Intervention period is not specified but intervention was evaluated after 4 months.	Justification – Research shows that community health interventions are an essential component of chronic disease management. Assessments in the intervention villages further underpinned the residents’ strong desire for services provided by community health workers.

8.6.4. Implementation Outcomes

A comprehensive assessment of implementation outcomes, in terms of acceptability, adoption, appropriateness, feasibility, implementation cost, penetration and sustainability, is shown in Table 3. Most of the included studies assessed only a few of these outcomes. As an example, implementation cost was only measured in one study, (54) while implementation adoption, appropriateness and penetration were measured in two studies. (45,50) Acceptability and feasibility were most commonly measured (both were measured in four studies (45, 49, 53, 52)

8.6.5. Diabetes-related outcomes

The diabetes-related outcomes described by study design, (RCT and non-RCT design) are summarised in Table 4 and detailed below.

8.6.5.1. Randomised controlled trials (Table 4)

Clinical outcomes

HbA1c

Of the 3 RCTs, only Mash et al. assessed HbA1c and found a 0.01% weighted mean reduction in HbA1c between intervention and control groups, which was neither statistically nor clinically significant. (47)

Fasting glucose and 2-hour postprandial glucose (FPG/PPG)

Zhong et al. was the only RCT, which examined changes in fasting glucose levels. The study showed a reduction from 7.68mmol/L to 6.76 mmol/L for the intervention group, while those in the control groups exhibited a slight increase from 6.38 mmol/L to 6.66 mmol/L. (45) The difference between these two patterns was statistically significant ($p < .001$), but the authors did not report on its clinical relevance.

Blood pressure

Two of three RCTs, Zhong et al. and Mash et al., (45,47) reported on blood pressure. These studies found significant reductions in systolic blood pressure (SBP) and diastolic blood pressure (DBP) in the peer/CHW-led interventions compared to the control groups.

Zhong et al (45) reported a significant reduction in SBP in their interventional group (136-128 mmHg) compared to the control group (130-131 mmHg) and in DBP (intervention 82.5-79.1 mmHg; control 79.0-78.6 mmHg). Mash et al. (47) reported a weighted mean SBP reduction of

4.65 mmHg (95% CI -9.18 to -0.12), which was not statistically significant. Further, a weighted mean DBP reduction of -3.30 mmHg (95% CI -5.35 to -1.26) was statistically significant.

Body mass index (BMI)

Only one RCT, Zhong et al. measured BMI, which was reduced in the peer-led intervention group from 24.3 kg/m² to 23.7 kg/m² ($p < 0.001$) whilst it increased in the control group from 23.5 kg/m² to 24 kg/m² ($p < 0.001$) between baseline and 12 months. (45)

Diabetes symptoms

Only Gargliardino et al. (46) reported changes in classical diabetes symptoms (polydipsia, polyuria, polyphagia, pruritus, and asthenia). The symptoms were statistically significantly reduced in both control and intervention groups between baseline and 12 months with no significant differences between control- and intervention reductions. The authors did not report whether these findings were clinically relevant.

Behavioural health outcomes

Self-management care outcome

Only two RCT studies reported on self-management care activities. Zhong et al. and Mash et al., (45,47) found no significant differences in self-management practices relating to diet, physical activity, glucose monitoring and medication adherence.

Physical activity

Two of the three RCTs reported on physical activity. Gargliardino et al. (46) demonstrated a significant reduction in the number of participants practicing regular physical activity in control (56% to 37%, $p = 0.0006$), but not the COMP-DSMPs intervention group (69% to 60%, $p = 0.221$). Notably, there was a significant difference in the reduction (in %) between the two groups (19% versus 9%, $p = 0.035$). Zhong et al. (45) reported no improvement in self-reported physical activity.

Psychological health outcomes

Self-efficacy

Although self-efficacy for diabetes management was measured using different scales, two RCT studies reported increased self-efficacy in the intervention group compared to the control group when measured at 6 to 12 months. Zhong et al. (45) found significant improvements in self-efficacy with the intervention in two out of six sites, where a COMP-DSMPs was implemented. However, Mash et al., (47) reported the COMP-DSMP-intervention did not improve psychological health outcomes including self-efficacy.

Diabetes knowledge.

Two RCT studies reported on diabetes knowledge. Zhong et al. (45) found statistically significant improvements at twelve months' follow-up in a knowledge domain made up of twelve items (four concerning glucose, three concerning diabetic complications, two concerning diet and three concerning insulin). However, the control group's knowledge diminished from baseline. Gargliardino et al. (46) showed that the attendees' knowledge increased significantly ($p < 0.01$) in both groups, but without any significant difference between intervention and control groups.

Depression, diabetes-related distress and quality of life

Gargliardino et al. (46) reported on diabetes-related distress, while Mash et al. (47) reported on depression. Neither study reported significant differences in these measurements in the intervention and control groups at baseline-to-12 months. Zhong et al. (45) did not report on any of these measures, and none of the RCTs reported on quality of life.

8.6.5.2. Pre-test/post-test and non-RCTs (Table 4)

Clinical outcomes

HbA1c

Four studies, Assah et al., Micikas et al., Baumann et al. and Less et al. (48, 49,50, 54) reported HbA1c as an outcome measure. Assah et al (48) reported a greater reduction in HbA1c in the peer-led intervention than the control group (difference = -1.7%, 95%CI: -2.2 to -1.3%, $p < 0.001$). The other three studies with significant improvements were quasi-experimental in design. Micikas et al. and Baumann et al. (49,50) reported the mean HbA1c decreased from 10.1% and 11.1% at

baseline to 8.9% and 8.3% at four months ($p=0.01$ and $p=0.005$) respectively. Less et al. (54) reported a reduction of 0.6% in mean HbA1c in the intervention group between baseline and six-month values and an increase of 0.6% in the control group, with the difference being statistically significant after controlling for potential confounders ($p<0.05$). (54)

Fasting blood glucose levels

Only Eggermont et al. (52) reported on blood glucose outcomes. The study demonstrated a statistically significant reduction in fasting blood glucose (10.0 mmol/l to 7.7 mmol/l, $p<0.001$) two years after baseline,

Blood pressure:

Two studies reported on blood pressure. Eggermont et al. (52) identified significant reductions in systolic (134 to 124 mmHg, $p<0.001$) and diastolic (85 to 77 mmHg, $p<0.001$) blood pressure. In contrast, Baumann et al. (50) reported that diastolic (85-76 mmHg, $p<0.001$) but not systolic (146-140 mmHg, $p=0.25$) blood pressure decreased significantly in the intervention group compared to the control group.

BMI

There was no difference found between- or within-group changes in BMI in the four studies where BMI was assessed. (49,52-53)

Behavioural health outcomes

Self-management care outcome

Three studies reported on self-management care activities. Assah et al. (48) found a significantly increased level of self-care activities in the intervention compared to the control group ($p < 0.001$). Baumann et al. (50) reported that the adherence to the eating plan improved from pre- to post-intervention ($p<0.005$), which was measured regarding a 'healthy eating index' created by the authors. However, there were no significant pre-/post-intervention changes in physical activity, missed medication, helpfulness of social support, emotional well-being, confidence, and barriers to self-care. Shen et al. (53) reported that overall self-management activities were significantly higher in the intervention group compared to the control group. However, self-management of diet and medication did not differ significantly between the two groups at four and twelve weeks. These analyses were adjusted for baseline variables and multiple comparisons.

Only Shen et al. (51) reported a reduction in the number of visits to a doctor (MD -0.73, $p=0.03$) and a community health centre (MD -0.60, $p=0.03$) in the intervention compared to the control group. However, there were no significant differences in the number of visits to the emergency room, the frequency of hospitalisation, or the days of hospitalisation between the groups at four or twelve weeks.

Physical activity

One study, by Micikas et al., (49) reported on physical activity. The study did not observe significant changes in the proportion of patients who exercised for ≥ 30 minutes per day after four months of the intervention (20% to 18%, $p=0.811$).

Psychological health outcomes

Self-efficacy

One study reported on self-efficacy. Baumann et al. (50) measured various aspects of self-efficacy including overall self-efficacy, and self-efficacy relating to diet, exercise, medication use, blood glucose testing, foot care, and hyperglycaemia/hypoglycaemia. At four weeks and twelve weeks, overall self-efficacy (both $p<0.021$) and self-efficacy relating to blood glucose testing (both $p<0.005$), foot-care (both $p<0.001$) and hyper-/hypoglycaemia (both $p<0.001$) were significantly higher in the intervention compared to the control group.

Diabetes knowledge

One study reported on diabetes knowledge. Micikas et al. (49) reported that the intervention (over four months) significantly improved diabetes knowledge about targets for HbA1C (6% to 42%, $p=0.001$); fasting blood glucose (19% to 87%, $p=0.001$); and the foods that raise blood glucose levels (13% to 31%, $p=0.032$). However, knowledge about the impact of emotions on blood glucose levels did not improve ($p=0.687$).

Depression, diabetes distress, quality of life

Two studies reported on these measures. Shen et al. (51) measured depressive status subdivided into 'overall depressive status', 'unhappy status', 'somatic status', 'interpersonal status', 'depressed affect status'. The mean score for 'unhappy status' decreased significantly in the intervention group between 4 and 12 weeks ($p=0.037$), while it did not change in the control

group ($p=0.26$). However, there were no significant differences between the intervention and control groups regarding 'overall depressive status', and 'somatic', 'interpersonal' and 'depressed affect status'. Rotheram-Borus et al. (53) evaluated diabetes distress in terms of coping skills, which was significantly improved between baseline and three months, but not between three and six months. Furthermore, spiritual hope decreased between three and six months ($p<0.01$).

Social support

Two studies reported on social support. Shen et al (51) identified that the intervention group had significantly higher overall social support (both $p<0.001$), information and emotional support (both $p<0.001$), positive interaction (both $p<0.001$), and affectionate support (both $p<0.001$) compared to the control group assessed at four and 12 weeks. However, the peer intervention failed to improve tangible support significantly (include assisting with transportation, helping with household chores, helping to prepare food, providing physical care, and providing financial help) at the same time intervals four and twelve weeks. Rotheram-Borus et al. reported improvements in social support ($p<0.01$) and positive action coping style ($p<0.01$) after three months. (53)

8.7.5. Implementation fidelity of all the included studies

Implementation fidelity refers to the extent to which a proposed intervention is enacted as designed. This measure is essential to determine to which extent the intervention in question is the primary mechanism underlying any changes observed (42,43). Table 5 summarises the adherence, moderators and assessment fidelity of the included studies in this review.

The moderators of fidelity refer to factors which may influence or moderate the degree of fidelity with which an intervention is implemented such as intervention complexity, facilitation strategies, quality of delivery, and participant responsiveness. (43, 55) We were able to monitor fidelity in three studies, which had published protocols. (45, 47, 51) The most frequently used indicator of fidelity was adherence (to the content, frequency and duration of the intervention). (45, 47, 51)

Three studies (45,47,51) refer to facilitating strategies to increase the implementation quality. In one study (47) the quality of the program delivery was used as a moderator. Overall, three studies (45, 47,51) used a questionnaire or interviews completed by the participants and providers. Two studies (47,51) combined a direct observation, recording of sessions and self-reported measures (questionnaire or interviews completed by the participants and providers) to assess the adherence to the program content.

Table 8–3 Assessment of implementation outcomes of diabetes self-management peer support strategies in LMIC by mode of intervention delivery.

Mode of delivery	Domain	Study design	Acceptability	Adoption	Appropriateness	Feasibility	Implementation Cost	Penetration	Sustainability	Available measurement/s
Peer	Zhong 2015 (45)	RCT	(+)	(+)	(+)	(+)	(-)	(+)	(+)	focus groups/ interviews/report/records
	Gargliardino, 2014 (46)	RCT	(-)	(-)	(-)	(+)	(-)	(-)	(-)	Structured questionnaire/interviews
	Assah, 2015 (48)	Non-RCT With a control arm	(-)	(-)	(-)	(-)	(-)	(-)	(-)	Structured questionnaires
	Baumann 2014 (50)	Pre/post	(+)	(-)	(-)	(+)	(-)	(+)	(+)	Report/ phone records/ questionnaires
	Huixia Shen 2008 (51)	Pre/post	(+)	(-)	(-)	(+)	(-)	(-)	(-)	Focus groups/report/records/ questionnaire
	Eggermont N 2011 (52)	Pre/post	(-)	(-)	(-)	(-)	(-)	(-)	(-)	Structured questionnaire/ in-depth interviews
	Rotheram-Borus 2012 (53)	Pre/post	(+)	(-)	(-)	(+)	(-)	(-)	(-)	Structured questionnaire/interviews
NCHWS	Mash, 2014 (47)	RCT	(-)	(-)	(-)	(-)	(-)	(-)	(-)	Interviews/report/records/ questionnaire
	Micikas M, 2014 (49)	Pre/post	(+)	(-)	(-)	(-)	(-)	(-)	(-)	Focus groups/ Structured questionnaires
	Less 2010 (54)	Pre/post	(-)	(-)	(-)	(-)	(+)	(-)	(+)	Structured questionnaire

Measured (+), None (-). NPCHW: Non-professional community health workers

Table 8–4 Summary of intervention effects on clinical, behavioural and psychological outcomes by study design

Authors year	Zhong 2015 (45)	Gargliardi no 2014 (46)	Mash 2014 (47)	Assah 2015 (48)	Micikas 2014 (49)	Baumann 2014 (50)	Huixia 2008 (51)	Eggermont 2011 (52)	Rotheram- Borus 2012 (53)	Less 2010 (54)
Design	RCT	RCT	RCT	Non- RCT wth control	Pretest- posttest (one-group)	Pretest- posttest (one-group)	Pretest- posttest with comparison group	Pretest posttest (one-group)	Pretest- posttest (one-group)	Pretest-posttest with comparison group
Sample size	n=229 C:94 I:135	n=198 C:105 I: 93	n=1570 C: 860 I:710	n=200 C: 96 I:96	n=100	n=46	n= 181 C: 89 I:92	n=3078	n=19	n=:318 C: 159 I:159
Duration of diabetes (year)	9.3	6	NR	NR	NR	6.7	NR	NR	NR	5-21
Follow-up (months)	12	12	12	6	4	4	3	24	6	6
HbA1C	NR	NR	↔	↓	↓	↓	NR	NR	NR	↓
FBG/PPG	↓	NR	NR	NR	NR	NR	NR	↓	NR	NR
BP	↓	NR	↓	NR	NR	↓ DBP	NR	↓	NR	NR
BMI	↓	↔	↔	NR	↔	NR	NR	↔	↔	↔
Diabetes symptoms	NR	↔	NR	NR	NR	NR	NR	NR	NR	NR
Clinical visits/hospitalisation	NR	NR	NR	NR	NR	NR	↔	NR	NR	NR
Self-management activities	↔	NR	↔	↑	NR	↔	↑	NR	NR	NR
Physical activity	NR	↔	NR	NR	↔	NR	NR	NR	NR	NR
Self-efficacy	↑	NR	↔	NR	NR	NR	↑	NR	NR	NR
Diabetes knowledge	↑	↑	NR	NR	↑	NR	NR	NR	NR	NR
Depression	NR	↔	↔	NR	NR	NR	↔	NR	↔	NR
Social support	NR	NR	NR	NR	NR	NR	↑	NR	↑	NR
Quality of life	NR	NR	↔	NR	NR	NR	↔	NR	NR	NR

↔ = no statistically significant differences ↑ = Significant increase ↓ = Significant decrease NR=not reported, HbA1C: glycated

haemoglobin, FBG/PPG: Fasting glucose and 2-hour postprandial glucose, BP: blood pressure, BMI: Body Mass Index, NR: Not Reported.

Table 8–5 Assessment of elements of implementation fidelity (Ref 43)

Study by Mode of intervention Delivery	Adherence				Moderators				Assessment					
	Content	Coverage	Frequency	Duration	Intervention complexity	Facilitation strategies	Quality of delivery	Participant responsiveness	Direct observation	Audio/vid eo tap	Provider question naire or checklist	Provider interview	Participants questionnaire	Participant s interview
Peers														
Zhong 2015 (45)	✓	NA	✓	✓	✓	✓	NA	✓	NA	✓	NA	✓	NA	✓
Gargliardino, 2014 (46)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Baumann. 2014 (50)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Huixia Shen 2008 (51)	✓	NA	✓	✓	NA	✓	NA	✓	✓	✓	✓	✓	✓	✓
Eggermont N 2011 (53)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Rotheram-Borus 2012 (53)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA

Assah, 2015 (48)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
NCHWs														
Mash, 2014 (47)	✓	NA	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓
Micikas M, 2014 (49)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Less 2010 (54)	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA

IF = Implementation Fidelity, NA = not assessed in the primary papers

8.7. Discussion

This systematic review found that COMP-DSMPs were inconsistently associated with improvements in clinical (45-48, 51) behavioural (45-47,48- 5) and psychological (45- 50 ,48) outcomes in LMIC. There was high variability in reported outcomes. As a consequence, meaningful meta-analysis or comparisons were not possible. The included studies only assessed short-term outcomes and no 'hard-endpoints' in terms of co-morbidity, microvascular, macrovascular events and mortality were reported.

Most included studies were of low-quality design with significant risks of bias particularly in relation to the blinding of outcomes. Furthermore, the majority of the non-RCT studies did not address issues surrounding selection bias or gave insufficient information regarding the selection process. The strategies employed were often not described in much detail and were poorly or not assessed regarding implementation fidelity. Finally, most of the studies reporting on clinical outcomes only evaluated the outcomes in terms of statistical significance and not clinical relevance. These results are discussed here in terms of implications for health care delivery, as well as implications for future design and implementation of studies of COMP-DSMPs in diabetes care delivery in LMIC.

Current literature, mainly from HIC supports the findings from this review that effects of COMP-DSMPs are equivocal. A systematic review by Webel et al. reported major heterogeneity between studies both in outcomes and designs, (56) while Dale et al. reported that peer-support seemed to benefit some adults living with diabetes, but suggested that the evidence was inconsistent and inadequate to support firm recommendations. (57) Large RCTs in HIC (58, 59) have also reported modest benefits for some, but not all outcomes assessed.

Throughout our analysis of the nature of the implementation strategies, we relied on the framework developed by Proctor et al. (40) While most of the studies touched on five of the six dimensions included in the taxonomy adapted for this study, none directly followed the Proctor framework and thus did not readily lend themselves to being evaluated using this framework. Further, none of the studies described temporality. This is at odds with the suggestion of Proctor et al. (40) that temporality be considered by researchers planning implementation/intervention programs and applied systematically across study populations, unless otherwise stated, to ensure that the experimental conditions are the same. Temporality can be a critical factor contributing to

the effectiveness of an implementation strategy, because peers'/CHWs' skills, knowledge, and engagement may decrease over time if not employed.

Few existing studies have employed Proctor's framework. Yet studies such as that of Powel et al. (60) illustrate the value of using such a standardised framework when they adopted the framework to report on a diabetes quality improvement intervention in its original commercial care setting and in community health care centres, in which actors, action, temporality, and dose were adapted to fit the local context. (60) The models of peer/CHW-led program need to be further explored, especially given the inevitability of a professional healthcare workforce shortage in LMIC.

Furthermore, COMP-DSMPs have the potential to fulfil the ideals of 'triple aims of health care' defined by the Institute for Healthcare Improvement, which involves improving a patient's experiences of care, improving the health of populations, and reducing per capita costs of care. Thus, COMP-DSMPs for diabetes deserve more attention. (61) Future studies should include an assessment of cost-effectiveness due to the limited data on this aspect of COMP-DSMPs. A single study in HIC from the UK revealed no significant differences in the final cost-effectiveness endpoints for a group-based peer support intervention for type 2 diabetes in general practice. (62) Mash et al. found that a structured group education programme delivered by health promoters at primary care clinics in South Africa for the management of Type 2 diabetes was cost-effective (63) Ideally, it would be important to assess cost-effectiveness in terms of traditional hard outcomes such as mortality and micro- and macro-vascular complications, but the longer length of follow-up and large sample sizes are likely to be costly. (63)

8.8. Conclusion

The evidence supporting the use of PSMSPs for people with diabetes in LMICs is equivocal.. We recommend well-designed studies using a framework such as the MRC framework for the development and evaluation of complex interventions to inform the evidence base on the contribution of COMP-DSMP in LMIC.

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Chapter 9

SUMMARY AND CONCLUSIONS

IMPLICATIONS FOR POLICY, PRACTICE AND FUTURE RESEARCH

9.1. Chapter outline

This body of work aimed to inform the development of a self-care management programme for older people attending public sector primary healthcare services in Cape Town, South Africa based within the PRECEDE planning model. This chapter summarises the main findings of the various studies which form part of this thesis. It also presents the implications of the findings for policy and practice, recommendations for future research, and strengths and limitations.

9.2. Principal findings

The key results framed within the PRECEDE planning model in this study are presented in Figure 9–1.

1. Epidemiological assessment

The systematic review of the prevalence of diabetes mellitus, the first estimate of the burden of type 2 diabetes among older people (>55yr) in Africa, found that type 2 diabetes is not rare in individuals of this age group across the continent (overall prevalence was 13·7 % (95% CI 11·3–16·3). In addition, the estimated prevalence of diabetes was twofold higher in studies that used an OGTT than in those that used FPG to diagnose diabetes, and that non-STEPs studies showed a prevalence 1.6 times higher than STEPS studies. The following data were not part of the planned epidemiological assessment but do provide important epidemiological insights. In an analysis of SAGE South Africa Wave 1 data, a 9.2% prevalence rate of self-reported diabetes was found and individuals with diabetes had at least twofold higher rates of coexisting chronic conditions than those without diabetes.

2.Social assessment

From the analysis of SAGE South Africa Wave 1 data, self-reported diabetes was associated with a lower quality of life and greater disability amongst older South Africans. Further, diabetes represented not only a risk factor for disability but was associated with a wide range of impairments and co-morbidities predisposing to loss of autonomy, as were sociodemographic characteristics (low education, being in a low wealth quintile, having a poor employment history, not being in a partnership), lifestyle habits (low physical activity, alcohol use) and co-morbid conditions. Nevertheless, study participants with and without diabetes who had a high level of physical activity were found to have higher quality of life scores.

3.Educational and ecological assessment

In the cross-sectional study of 406 adults aged 60 years or more undertaken in the Cape Town Metropole primary care clinics, half of the participants had a poor knowledge level in relation to symptoms and complications of diabetes, but most participants received family support to follow aspects of diabetes self-management. Subsequent regression analyses showed older age was negatively associated with knowledge, higher income was associated with self-management practice and family support was positively associated with the score for a number of specific self-management practices as well as with a knowledge score. This may be of an advantage in many cultures, such as in South Africa, where strong family relationships and informal care from family and friends are essential and highly valued.

4.Administrative, policy and intervention-alignment assessment

Step A: To get an understanding of current policies and programmes that relate to older people with diabetes, a review of policies and programmes and qualitative individual interviews with key informants (KI) were conducted. There was a consensus among KIs that generally older persons wanted to be 'compliant', but they faced numerous barriers in managing their condition. There are multiple efforts to re-orientate the healthcare system to focus more effectively on NCDs for the population, which would benefit older patients with diabetes.

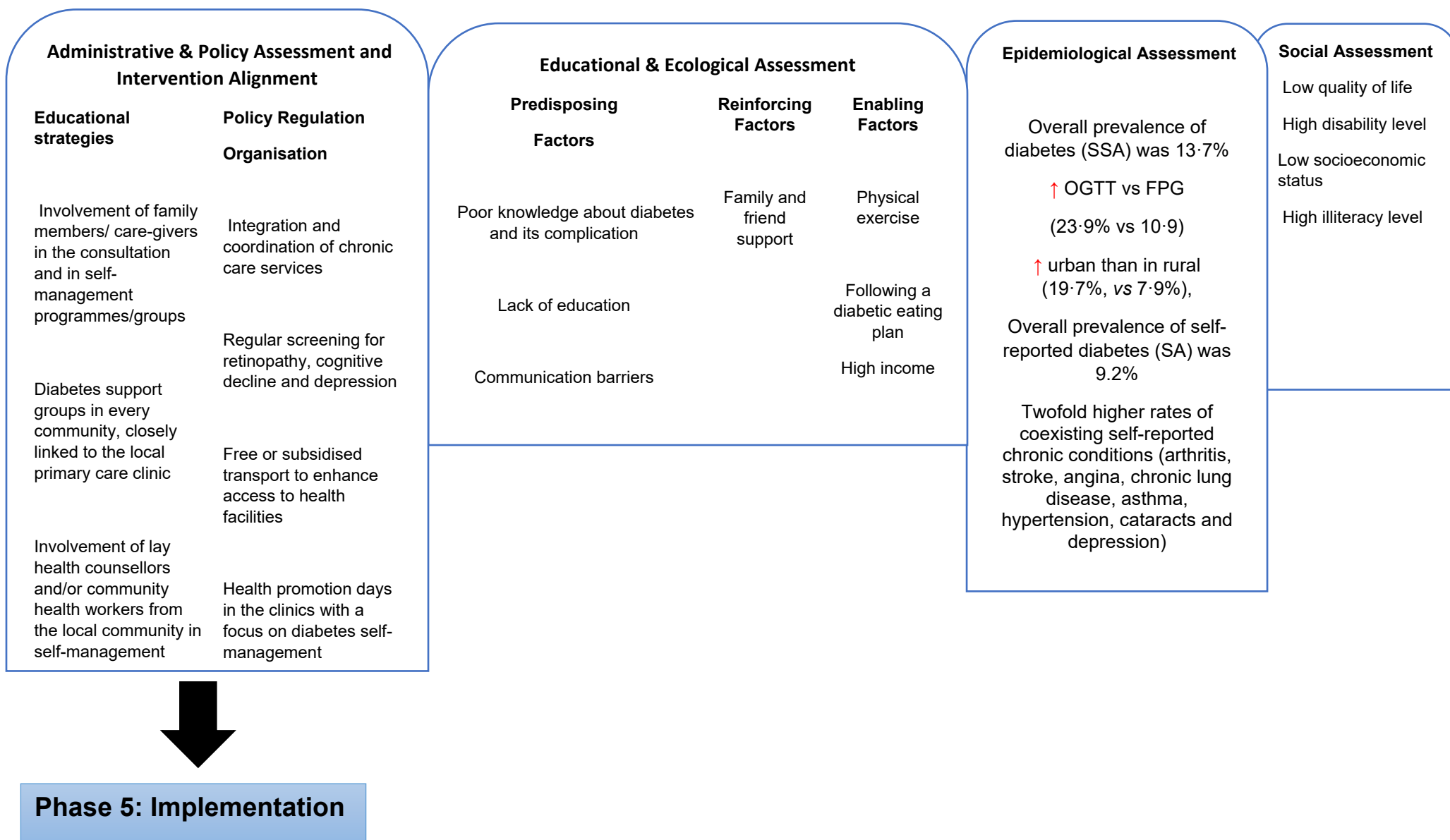
Older people were keen to engage on matters relating to their health, thereby making it feasible for health care providers to interact with older persons and play a more active role in enhancing health literacy, health promotion and self-management. What was not mentioned by the key informants – but which may be of equal importance – is that healthcare providers need to gain appropriate communication skills and educational resources to effectively educate and counsel older persons on lifestyle behaviour change and self-care. The current gaps in knowledge of

diabetes in this population group it is critical for establishing evidence-based practice which necessitates identifying research priorities, allocating resources, and setting health care policies.

Step B:

The second systematic review explored community-based peer and community health worker-led diabetes self-management programmes (COMP-DSMP) in low and middle-income countries' (LMIC) primary care settings and evaluated implementation strategies and diabetes-related health outcomes. The main review findings were that the effects of COMP-DSMP were equivocal. While these findings are in keeping with studies from High-Income Countries, many of the studies included in the review were evaluated as being of a low quality.

Figure 9–1 Application of PRECEDE planning model for development self-management care for older people in Cape Town City, South Africa



9.3. Implications for policy and practice

The work underpinning this thesis has a number of implications for policy and practice.

There is a clear need to invest in surveillance, diabetes prevention, and creation of affordable, innovative models of health-care access and systems to halt the growing burden of diabetes in Africa.

For successful monitoring of secular trends in the incidence and prevalence of diabetes in older people, associated with the epidemiological transition across all African countries, the use of standardised methods is necessary. National and not subnational samples should be studied. While using the OGTT would be ideal in epidemiological studies of older people, this is not likely to be implementable across the region due to cost and inconvenience. HbA1c would be the simplest indicator, as it avoids the need for fasting and measurement of glucose concentrations at two hours for an OGTT, but the cost and lack of data regarding the diagnostic cut point in Africa are among the potential barriers. There will need to be general acknowledgement that the use of FBG alone will underestimate the true prevalence and thus burden.

This study highlights a need to fill gaps in the knowledge towards improving quality of life and meeting care needs in older persons with diabetes. Multimorbidity is common among the older persons, the management of which requires integration and coordination of chronic care services. Poor health literacy related to low educational attainment and limited access to information among older persons is a known contributing factor to suboptimal diabetes outcomes among this group. There is a need for educational material to be provided in the form of simple messages, delivered in a style that engages the person with diabetes and is personalised to their needs, with the emphasis on what he/she needs to know, rather than all there is to know about diabetes. This study recommends sustainable policies to promote healthy lifestyle behaviours, increase physical activity and manage health conditions, across the life course. This requires identifying research priorities, allocating resources, the designing and testing of new integrated care models targeted at older people within the roll-out of universal health coverage.

In this study social support was positively associated with better knowledge and diabetes self-management practices. Consideration needs to be given to developing and evaluating education programmes that focus on the needs of older persons with diabetes and emphasises the role of family and friends. For instance, groups held outside of primary care clinics in the community and

led by trained CHWs may be a better option, so too may the active participation by family members in these groups. It is imperative to introduce such programmes at a younger age so that diabetes self-management strategies are embedded as a life course perspective to enhance positive outcomes for persons living with diabetes.

The models of a peer/community health worker-led programme need to be further explored, especially given the inevitability of a professional healthcare workforce shortage in LMICs, particularly in the public sector primary health care services in South Africa. Furthermore, community-based peer and community health worker-led diabetes self-management programmes (COMP-DSMPs) have the potential to fulfil the ideals of ‘triple aims of healthcare’ which involves improving a patient’s experiences of care, improving the health of populations, and reducing per capita costs of care. Thus, COMP-DSMPs for diabetes deserve more attention. As clearly documented by the key informants in this study, the establishment of community-based services to provide self-management support, promote health and easy access to medicine, as well as home visits by district-based CHWs, help to overcome many of the barriers to care experienced by older persons. It enables services to be delivered early and close to home, decreases waiting times, reduces transport and other associated costs for older persons and provides for continuity of care.

9. 4. Implications for future research

First, a dearth of research as evidenced in the systematic reviews in this study on leading health issues such as diabetes in older adults in sub-Saharan African countries impacts health policy and planning. Evidence-based policy and planning on services for older clients is underdeveloped or lacking in the sub-continent, partially due to epidemiological and demographic transitions being recent and more rapid than in high-income countries and as well as to competing interests for resources. Second, future studies should assess the prevalence of type 2 diabetes according to uniform case definition and diagnostic methods and provide standardised prevalence values for older people across Africa to enable comparisons within countries and across the continent.

Third, future research must focus on care models that improve outcomes in this age group while preserving (and improving) the quality of life. This should be guided by outcomes relevant to the patient group and their families. Future research should focus on developing and evaluating family/friends-focused community-based multi-disciplinary education programmes and on improving self-care practices among older individuals attending primary care clinics. Fourthly, qualitative research is required to address in depth those research questions which relate to the

impact of factors such as retirement, low income, living arrangements, age-friendly vs ageist attitudes of health professionals towards older clients, and the promotion of health behaviours.

Fifth, this study recommends well-designed studies using a framework such as the MRC framework for the development and evaluation of complex interventions to inform the evidence base on the contribution of COMP-DSMP in LMICs, particularly in a limited-resource setting such as the public sector primary health care services in South Africa.

9.5. Strengths and limitations of this research study

This study contributes to an understanding and fills a gap in the current knowledge of a number of issues relating to diabetes in the older person in South Africa and particularly relating to diabetes self-management practices, and perceived social support from family and friends for their care. However, the study has some limitations. Ideally, the work would have progressed to the PROCEED or implementation phases of the PRECEDE-PROCEED model but due to limited resources available for the present body of work, only the (PRECEDE) four phases (phase 1–phase 4) were conducted. For pragmatic reasons, the lower age for definition for the older person was not consistent across all the studies. For example, the systematic review of the prevalence of diabetes in Africa included people of 55 years and older because of lack of consistency in the age bands used in many studies from the region. The SAGE survey included people over the age of 50 years, but analyses included different age groups above this age.

The studies based on the SAGE survey and in community health centres in Cape Town were both cross sectional and as such could not assess cause and effect. In the latter, the measurements were self-reported rather than direct observation of self-care practices and, the use of a convenience sample drawn from a population who attend a diabetes clinic excludes those who did not attend. Because of the small number of key informants interviewed and its limitation to one region only, the study may not be representative of all older South Africans with diabetes, thus impacting on the generalisability of the findings.

The lack of in-depth interviews and focus group discussions with older people with diabetes and their support network would have added to a better understanding of enablers and barriers to effective self-management. Lastly, rigorous methods were used in the systematic reviews, however, for the systematic review on the effectiveness of peer and COMP-DSMP in LMICs, the differences in study designs, outcomes, the scale of measurements, and measurement times precluded meta-analysis and only provided for a narrative summary of the findings across studies.

The study does, however, have a number of strengths. It was undertaken within a well-recognised model used in health promotion, it made use of a mixed methods approach, including rigorous methods for the systematic reviews and has focused on a group that has received little attention to date.

In conclusion, this research study has described the extent of the proposed need for developing and evaluating education programmes that focus on older people with diabetes mellitus and emphasises the role of family and friends. Whilst there have been some significant policy interventions pertaining to the protection of the health and welfare of older persons in SA, the needs of this vulnerable group remain relatively low on the list of priorities in terms of focus and resource allocation. In this context, older people, as a distinct group, are also not a strong focus in current health policy relating to the provision of NCD care. This thesis alerts policymakers and clinicians to some of the specific issues considered to be pertinent and important in the care and management of older persons with diabetes. Many of these would also be applicable to older individuals with other chronic conditions.

10. APPENDICES

10.1. Appendix 1: the prevalence of type 2 diabetes mellitus among older people in Africa: a systematic review protocol.

10.2. Appendix 2: Effectiveness of community-based peer led diabetes self-management programmes (COMP-DSMP) for improving clinical outcomes and quality of life of adults with diabetes in primary care settings in Low and middle-income countries (LMICS): a systematic review protocol.

10.3. Appendix 3: Ethics approval.

10 .4. Appendix 4: Study 1: Supplementary Materials.

10 .5. Appendix 5: Study 2: Supplementary Materials.

10 .6 Appendix 6: Study 3: Supplementary Materials.

10 .7 Appendix 7: Study 4: Supplementary Materials.

10 .8 Appendix 8: Study 5: Supplementary Materials.

10.1 Appendix 1: the prevalence of type 2 diabetes mellitus among older people in Africa: a systematic review protocol.

Open Access

Protocol

BMJ Open The prevalence of type 2 diabetes mellitus among older people in Africa: a systematic review study protocol

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ABSTRACT

Introduction: The number of people with diabetes in Africa is projected to increase substantially in the next two decades, due to factors including rapid urbanisation, adoption of unhealthy diets and exercise patterns and the ageing of the population. There are currently uncertainties regarding the incidence, prevalence and management patterns of diabetes in older people across the diversity of African countries. We wish to perform a systematic review to determine the prevalence of type 2 diabetes in Africa in the older individual, over the age of 55 years, reported in studies from 2000 to 2013.

Methods and analyses: A comprehensive literature search among a number of databases will be undertaken, using an African search filter to identify diabetes prevalence studies that were published from 2000 to 2013. Full copies of articles identified by the search, and considered to meet the inclusion criteria, will be obtained for data extraction and synthesis. Statistical analysis of the primary measures, fasting plasma glucose (FPG) and oral glucose tolerance test will include two steps: (1) identification of data sources and documenting estimates and (2) application of the random-effects meta-analysis model to aggregate prevalence estimates and account for between study variability in calculating the overall pooled estimates and 95% CI for diabetes prevalence. Heterogeneity will be evaluated using the I^2 statistic to determine the extent of variation in effect estimates that is due to heterogeneity rather than chance. This systematic review will be reported according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA).

Ethics and dissemination: Ethics is not required for this study, given that this is a protocol for a systematic review, which utilises published data. The findings of this study will be widely disseminated through peer-reviewed publications and conference presentations.

INTRODUCTION

The most recent International Diabetes Federation (IDF) estimates from 2013 are that 8.3% of adults that is, 382 million

people worldwide have diabetes. This number has doubled over the past 20 years, and notably 80% of people with diabetes live in low and middle income countries (LMIC).¹ Diabetes already contributes significantly to morbidity and mortality in Africa. The highest global age-specific mortality rate is recorded in this continent.^{2–6} All countries in Africa fall into the LMIC category, and predominantly the low income category. The rise in the number of individuals with type 2 diabetes in Africa, similar to LMIC has been attributed to ageing of the population and relatively rapidly changing environmental factors.¹ These include urbanisation, the adoption of health behaviours favouring sedentariness and unhealthy eating patterns. While unhealthy behaviour patterns and obesity are potentially modifiable, ageing, one of the major drivers for diabetes, is not.⁷ In 2013, the majority of individuals with diabetes in Africa were reported to be under 60 years of age with the highest proportion (43.2%) in people aged 40–59 years.⁷ The relatively small proportion of individuals aged 60–79 years in the region is likely to account for the estimate that only 18.8% of patients with diabetes fall in this age group.¹

Africa is often referred to as the youngest continent in terms of age structure. This may contribute to the current relatively low prioritisation of ageing issues in national policies.⁸ Yet the annual growth rate of older persons in Africa has been estimated at 3.1% between 2007 and 2015, and 3.3% between 2015 and 2050, greater than the global average. In this context, it is concerning that there will be approximately 64.5 million Africans aged ≥ 55 years in 2015, and more than 103 million and 205 million in 2030 and 2050, respectively.⁶ Indeed it has been predicted that the diabetes peak in Africa is expected to be in the oldest individual by 2035.¹ We therefore wish to perform a

10.2 Appendix 2: Effectiveness of community-based peer led diabetes self-management programmes (COMP-DSMP) for improving clinical outcomes and quality of life of adults with diabetes in primary care settings in Low and middle-income countries (LMICS): a systematic review protocol.

Open Access

Protocol

BMJ Open Effectiveness of community-based peer-led diabetes self-management programmes (COMP-DSMP) for improving clinical outcomes and quality of life of adults with diabetes in primary care settings in low and middle-income countries (LMIC): a systematic review and meta-analysis

Mahmoud Werfalli,¹ Peter Raubenheimer,² Mark Engel,^{2,3} Nasheeta Peer,⁴ Sebastiana Kalula,^{3,5} Andre P Kengne,⁶ Naomi S Levitt¹

To cite: Werfalli M, Raubenheimer P, Engel M, *et al.* Effectiveness of community-based peer-led diabetes self-management programmes (COMP-DSMP) for improving clinical outcomes and quality of life of adults with diabetes in primary care settings in low and middle-income countries (LMIC): a systematic review and meta-analysis. *BMJ Open* 2015;5:e007635. doi:10.1136/bmjopen-2015-007635

► Prepublication history and additional material is available. To view visit the journal (<http://dx.doi.org/10.1136/bmjopen-2015-007635>).

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CrossMark

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ABSTRACT

Introduction: Globally, an estimated 380 million people live with diabetes today—80% in low-income and middle-income countries. The Middle East, Western Pacific, Sub-Saharan Africa and South-East Asia remain the most affected regions where economic development has transformed lifestyles, people live longer and there is an increase in the adult population. Although peer support has been used in different conditions with varied results, yet there is limited evidence to date supporting its effectiveness, particularly for individuals with diabetes. In this review, we will focus on community-based peer-led diabetes self-management programmes (COMP-DSMP) and examine the implementation strategies and diabetes-related health outcomes associated with them in LMIC primary healthcare settings.

Methods and analysis: In accordance with reporting equity-focused systematic reviews PRISMA-P (preferred reporting items for systematic review and meta-analysis protocols 2015 checklist) guidelines, a systematic review with meta-analysis of randomised controlled trials (RCTs), non-randomised controlled trials, quasi-randomised controlled trials (CCTs) that involve contact with an individual or group of peers (paid or voluntary). Electronic searches will be performed in The Cochrane Library, MEDLINE, PubMed, SCOPUS, CINAHL and PsycINFO Database for the period January up to July 2000 along with manual searches in the reference lists of relevant papers. The analyses will be performed based on baseline data from RCTs, CCTs and preintervention and postintervention means or proportions will be reported for both intervention and control groups, and the absolute change from baseline will be calculated, together with 95% CIs. For dichotomous outcomes,

the relative risk of the outcome will be presented compared to the control group. The risk difference will be calculated, which is the absolute difference in the proportions in each treatment group.

Ethics and dissemination: Ethics is not required for this study, given that this is a protocol for a systematic review, which utilises published data. The findings of this study will be widely disseminated through peer-reviewed publications and conference presentations.

Trial registration number: PROSPERO (2014: CRD42014007531).

BACKGROUND

Globally, an estimated 380 million people live with diabetes today—80% in low-income and middle-income countries (LMIC). These countries are also predicted to experience more than a twofold greater increase in the number of people with diabetes over the next 20 years than high-income countries.¹ The Middle East, Western Pacific, sub-Saharan Africa and South-East Asia remain the most affected regions, where economic development has transformed lifestyles,¹ people live longer and there is an increase in the adult population.^{1 2} Furthermore, socioeconomic status (SES) is considered to be a crucial determining factor of health, a significant contributor to health disparities and may play a role in the increasing prevalence of diabetes and related complications. Typically, low SES is associated with poorer access to healthcare.³

BMJ

Werfalli M, *et al.* *BMJ Open* 2015;5:e007635. doi:10.1136/bmjopen-2015-007635

1

10.3 Appendix 3: Ethics approval



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925

Telephone [021] 406 6338 • Facsimile [021] 406 6411

Email: shuretta.thomas@uct.ac.za

Website: www.health.uct.ac.za/research/humanethics/forms

13 January 2014

HREC REF: 709/2013

Prof N Levitt

Chronic Disease Initiative for Africa (CDIA)
J47-85, OMB

Dear Prof Levitt

PROJECT TITLE: DEVELOPING OF SELF-MANAGEMENT CARE PROGRAMME FOR OLDER PEOPLE WITH TYPE 2 DIABETES ATTENDING COMMUNITY HEALTH CENTRES IN CAPE TOWN METROPOLE

Thank you for your letter to the Faculty of Health Sciences Human Research Ethics Committee dated 19th December 2013.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30th January 2015

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/research/humanethics/forms)

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC reference no in all your correspondence.

Yours sincerely

PP *Tubogesi*

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Study 1: Supplementary Materials

This appendix formed part of the original submission and has been peer reviewed.

**Supplement to: Werfalli M, Engel ME, Musekiwa A, Kengne AP, Levitt NS. The prevalence of type 2 diabetes among older people in Africa: a systematic review. *Lancet Diabetes Endocrinol* 2015; published online Nov 5.
[https://doi.org/10.1016/S2213-8587\(15\)00363-0](https://doi.org/10.1016/S2213-8587(15)00363-0)**

Appendix 4: Describing the stages of search strategy

A. African Search Filter ⁹

The African Search Filter

("Africa"[MeSH] OR Africa*[tw] OR Algeria[tw] OR Angola[tw] OR Benin[tw] OR Botswana[tw] OR "Burkina Faso"[tw] OR Burundi[tw] OR Cameroon[tw] OR "Canary Islands"[tw] OR "Cape Verde"[tw] OR "Central African Republic"[tw] OR Chad[tw] OR Comoros[tw] OR Congo[tw] OR "Democratic Republic of Congo"[tw] OR Djibouti[tw] OR Egypt[tw] OR "Equatorial Guinea"[tw] OR Eritrea[tw] OR Ethiopia[tw] OR Gabon[tw] OR Gambia[tw] OR Ghana[tw] OR Guinea[tw] OR "Guinea Bissau"[tw] OR "Ivory Coast"[tw] OR "Cote d'Ivoire"[tw] OR Jamahiriya[tw] OR Jamahiriya[tw] OR Kenya[tw] OR Lesotho[tw] OR Liberia[tw] OR Libya[tw] OR Libya[tw] OR Madagascar[tw] OR Malawi[tw] OR Mali[tw] OR Mauritania[tw] OR Mauritius[tw] OR Mayotte[tw] OR Morocco[tw] OR Mozambique[tw] OR Mozambique[tw] OR Namibia[tw] OR Niger[tw] OR Nigeria[tw] OR Principe[tw] OR Reunion[tw] OR Rwanda[tw] OR "Sao Tome"[tw] OR Senegal[tw] OR Seychelles[tw] OR "Sierra Leone"[tw] OR Somalia[tw] OR "South Africa"[tw] OR "St Helena"[tw] OR Sudan[tw] OR Swaziland[tw] OR Tanzania[tw] OR Togo[tw] OR Tunisia[tw] OR Uganda[tw] OR "Western Sahara"[tw] OR Zaire[tw] OR Zambia[tw] OR Zimbabwe[tw] OR "Central Africa"[tw] OR "Central African"[tw] OR "West Africa"[tw] OR "West African"[tw] OR "Western Africa"[tw] OR "Western African"[tw] OR "East Africa"[tw] OR "East African"[tw] OR "Eastern Africa"[tw] OR "Eastern African"[tw] OR "North Africa"[tw] OR "North African"[tw] OR "Northern Africa"[tw] OR "Northern African"[tw] OR "South African"[tw] OR "Southern Africa"[tw] OR "Southern African"[tw] OR "sub Saharan Africa"[tw] OR "sub Saharan African"[tw] OR "sub-Saharan Africa"[tw] OR "sub-Saharan African"[tw]) NOT ("guinea pig"[tw] OR "guinea pigs"[tw] OR 'aspergillums Niger'[tw])

B. Describing the relevant search terms used in search strategy.

Elderly	"aged"[MeSH Terms] OR "aged"[All Fields] OR "elderly"[All Fields]
People	"persons"[MeSH Terms] OR "persons"[All Fields] OR "people"[All Fields]
Diabetes mellitus	"diabetes mellitus"[MeSH Terms] OR ("diabetes"[All Fields] AND "mellitus"[All Fields]) OR "diabetes mellitus"[All Fields]
Type 2 diabetes	"diabetes mellitus, type 2"[MeSH Terms] OR "type 2 diabetes mellitus"[All Fields] OR "type 2 diabetes"[All Fields]
Africa	"Africa"[MeSH Terms] OR "Africa"[All Fields]
Diabetes	"diabetes mellitus"[MeSH Terms] OR ("diabetes"[All Fields] AND "mellitus"[All Fields]) OR "diabetes mellitus"[All Fields] OR "diabetes"[All Fields] OR "diabetes insipidus"[MeSH Terms] OR ("diabetes"[All Fields] AND "insipidus"[All Fields]) OR "diabetes insipidus"[All Fields]
Prevalence	"epidemiology"[Subheading] OR "epidemiology"[All Fields] OR "prevalence"[All Fields] OR "prevalence"[MeSH Terms]

C. Describing electronic databases searches by using of African Search Filter

(elderly)) AND (elderly people)) AND (diabetes mellitus)) AND (type2 diabetes mellitus)) AND (type 2 diabetes)) AND (Africa)) AND (("Africa"[MeSH] OR Africa*[tw] OR Algeria[tw] OR Angola[tw] OR Benin[tw] OR Botswana[tw] OR "Burkina Faso"[tw] OR Burundi[tw] OR Cameroon[tw] OR "Canary Islands"[tw] OR "Cape Verde"[tw] OR "Central African Republic"[tw] OR Chad[tw] OR Comoros[tw] OR Congo[tw] OR "Democratic Republic of Congo"[tw] OR Djibouti[tw] OR Egypt[tw] OR "Equatorial Guinea"[tw] OR Eritrea[tw] OR Ethiopia[tw] OR Gabon[tw] OR Gambia[tw] OR Ghana[tw] OR Guinea[tw] OR "Guinea Bissau"[tw] OR "Ivory Coast"[tw] OR "Cote d'Ivoire"[tw] OR Jamahiriya[tw] OR Jamahiriya[tw] OR Kenya[tw] OR Lesotho[tw] OR Liberia[tw] OR Libya[tw] OR Libya[tw] OR Madagascar[tw] OR Malawi[tw] OR Mali[tw] OR Mauritania[tw] OR Mauritius[tw] OR Mayotte[tw] OR Morocco[tw] OR Mozambique[tw] OR Mozambique[tw] OR Namibia[tw] OR Niger[tw] OR Nigeria[tw] OR Principe[tw] OR Reunion[tw] OR Rwanda[tw] OR "Sao Tome"[tw] OR Senegal[tw] OR Seychelles[tw] OR "Sierra Leone"[tw] OR Somalia[tw] OR "South Africa"[tw] OR "St Helena"[tw] OR Sudan[tw] OR Swaziland[tw] OR Tanzania[tw] OR Togo[tw] OR Tunisia[tw] OR Uganda[tw] OR "Western Sahara"[tw] OR Zaire[tw] OR Zambia[tw] OR Zimbabwe[tw] OR "Central Africa"[tw] OR "Central African"[tw] OR "West Africa"[tw] OR "West African"[tw] OR "Western Africa"[tw] OR "Western African"[tw] OR "East Africa"[tw] OR "East African"[tw] OR "Eastern Africa"[tw] OR "Eastern African"[tw] OR "North Africa"[tw] OR "North African"[tw] OR "Northern Africa"[tw] OR "Northern African"[tw] OR "South African"[tw] OR "Southern Africa"[tw] OR "Southern African"[tw] OR "sub Saharan Africa"[tw] OR "sub Saharan African"[tw] OR "sub-Saharan Africa"[tw] OR "sub-Saharan African"[tw]) NOT ("guinea pig"[tw] OR "guinea pigs"[tw] OR 'aspergillums Niger'[tw])) AND (diabetes prevalence) AND ("epidemiology"[Subheading] OR "epidemiology"[All Fields] OR "prevalence"[All Fields] OR "prevalence"[MeSH Terms])

Appendix 5: Quality appraisal of included studies adapted (Hoy et al) (14) and modified by (Werfalli et al) (15)

Table 1 Quality assessment criteria for prevalence studies¹²

Items	Quality score
External validity	
1. Was the study's target population a close representation of the national population in relation to relevant variables?	(1 point)
2. Was the sampling frame a true or close representation of the target population?	(1 point)
3. Was some form of random selection used to select the sample, OR was a census undertaken?	(1 point)
4. Was the likelihood of non-response bias minimal?	(1 point)
	Total (4 points)
Internal validity	
1. Were data collected directly from the participants (as opposed to a proxy)?	(1 point)
2. Was an acceptable case definition used in the study?	(1 point)
3. Was the study instrument that measured the parameter of interest shown to have validity and reliability?	(1 point)
4. Was the same mode of data collection used for all participants? (1 point)	(1 point)
5. Was the length of the shortest prevalence period for the parameter of interest appropriate?	(1 point)
6. Were the numerator(s) and denominator(s) for the parameter of interest appropriate?	(1 point)
	Total (6 points)

Bias	Author's judgment	Support for Judgment
Risk of bias 1		
Risk of bias 2		
Risk of bias 3		
Risk of bias 4		
Risk of bias 5		
Risk of bias 6		
Risk of bias 7		
Risk of bias 8		
Risk of bias 9		
Risk of bias 10		
		11. Overall risk of bias

Please choose one of these keys to express the overall risk of bias

(0-5 points)



(6-8 points)



(>8 points)



LOW RISK OF BIAS: Further research is very unlikely to change our confidence in the estimate.

MODERATE RISK OF BIAS: Further research is likely to have an important impact on our confidence in the estimate and may change the estimate.

HIGH RISK OF BIAS: Further research is very likely to have an important impact on our confidence in the estimate and is likely to change the estimate.

Appendix 6: DATA EXTRACTION FORM

STUDY ID:

Reviewer's Initials

Part 1: COVERSHEET

Study Title

Journal:

Language:

Citation:

Part 2: STUDY CHARACTERISTICS.

Publication Year:

Country of study:

Study design:

- ☐ cross-sectional
- ☐ case-report
- ☐ other

Study period:

Data source:

- ☐ medical records
- ☐ special survey
- ☐ multiple source
- ☐ surveillance
- ☐ registries

Setting

- ☐ Urban
- ☐ Rural

Population study:

- ☐ total population
- ☐ specific group population
- ☐ other _____

Diagnostic Criteria.

- ❖ WHO Criteria: (Y / N).
- ❖ Measured or Defined by:
 - Fasting plasma glucose (FPG) ☐
 - glucose tolerance test (OGT) ☐
 - Self-reported ☐

❖ Please use the attached checklist (Tick as appropriate (✓))

Inclusion criteria: ☐ ☐ ☐ ☐ ☐

Exclusion Criteria: ☐ ☐ ☐ ☐ ☐

Included ☐ Excluded ☐ pending ☐

Age groups included (describe):

Genders included: (Total numbers)

Male ☐

Female ☐

Both ☐

Dominator (s) (N):

Reason(s) for exclusion, uncertainty or to contact authors

- 1.
- 2.
- 3.

Part 3: RESULTS.

Measure of the prevalence

- ☐ Crude Measure
- ☐ Adjusted measure

If **adjusted** what factors were adjusted for in this study (list):

Reported measure of the prevalence:



Missing data to be reported from the author:

(any communication with author Yes ☐ No ☐

If yes, please specify



Other comments:



Appendix 7: Summary of risk of bias of the included studies.

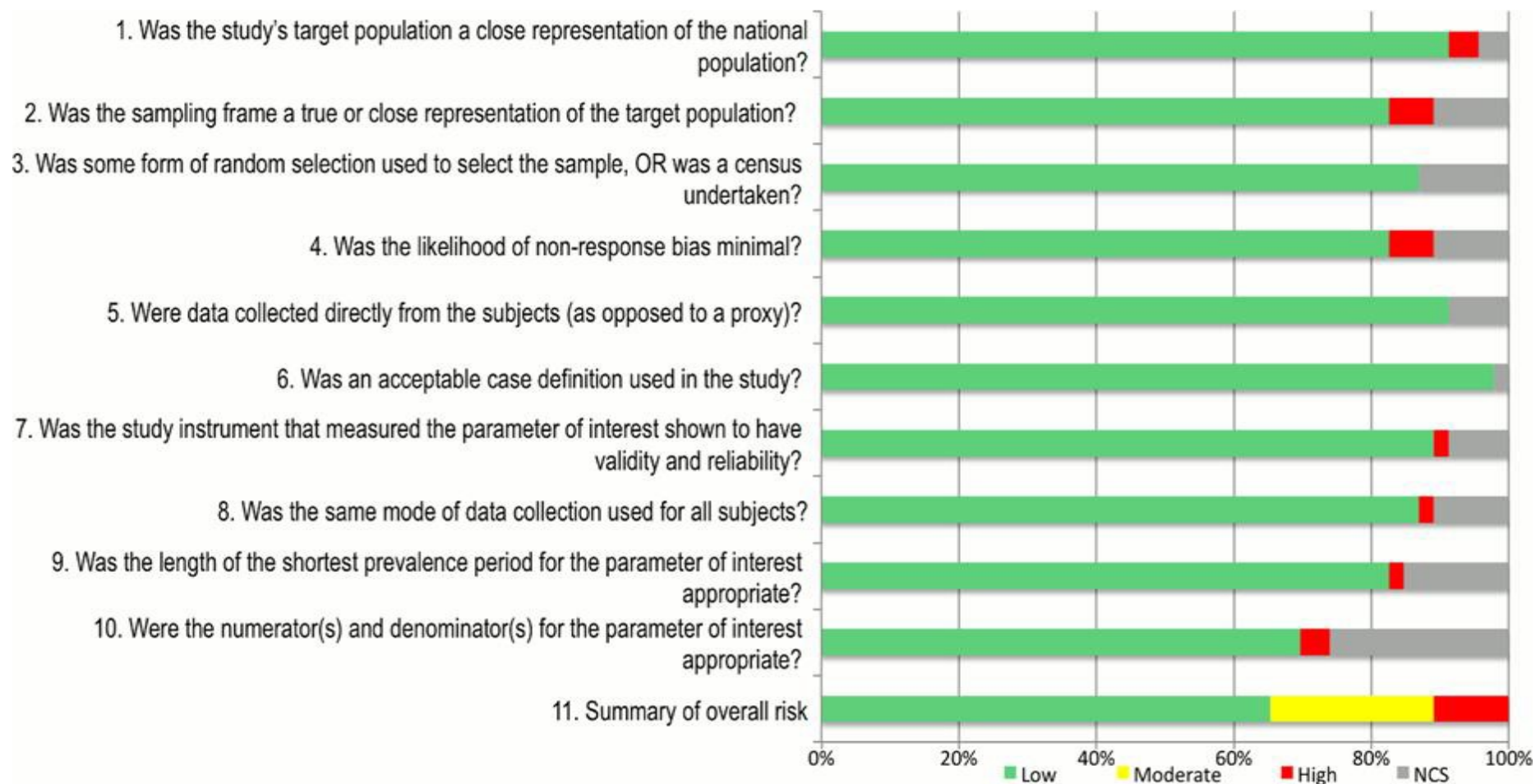
Country	Author/Year	Eternal Validity				Internal Validity						Overall risk of bias
		<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	<i>Risk of bias</i>	
		<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>	<i>8</i>	<i>9</i>	<i>10</i>	
Algeria	Malek 2001	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Algeria	Zaoui 2007	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Algeria	2003	NCS	NCS	Low	Low	Low	Low	Low	Low	Low	NCS	Moderate
Angola	Evaristo 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Benin	2008	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Botswana	2007	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Cameroon	Nchanchou 2008	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Canary Islands	Boronat 2005	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Congo	2004	Low	NCS	NCS	NCS	Low	Low	Low	NCS	Low	NCS	High

DRC	Onkin 2008	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
DRC	Katchunga 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
DRC	2006	High	Low	Low	High	Low	Low	Low	Low	Low	High	Moderate
Egypt	2006	Low	Low	Low	Low	Low	Low	Low	Low	NCS	NCS	Moderate
Ethiopia	Muluneh 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Ethiopia	Tran , 2011	Low	Low	NCS	NCS	Low	Low	NCS	NCS	NCS	NCS	High
Gabon	2009	NCS	NCS	Low	Low	Low	Low	Low	Low	NCS	Low	Moderate
Ghana	Amoah,,2002	High	NCS	NCS	High	Low	Low	High	Low	NCS	NCS	High
Guinea	Balde 2007	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Kenya	Ayah 2013	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
La Reunion	Favier 2005	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Libya	Kadiki 2001	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Libya	2009	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Malawi	2010	Low	Low	Low	NCS	Low	Low	Low	Low	Low	Low	Low
Mayotte	Solet 2011	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Mauritania	2006	Low	Low	Low	High	Low	low	Low	Low	NCS	NCS	Moderate

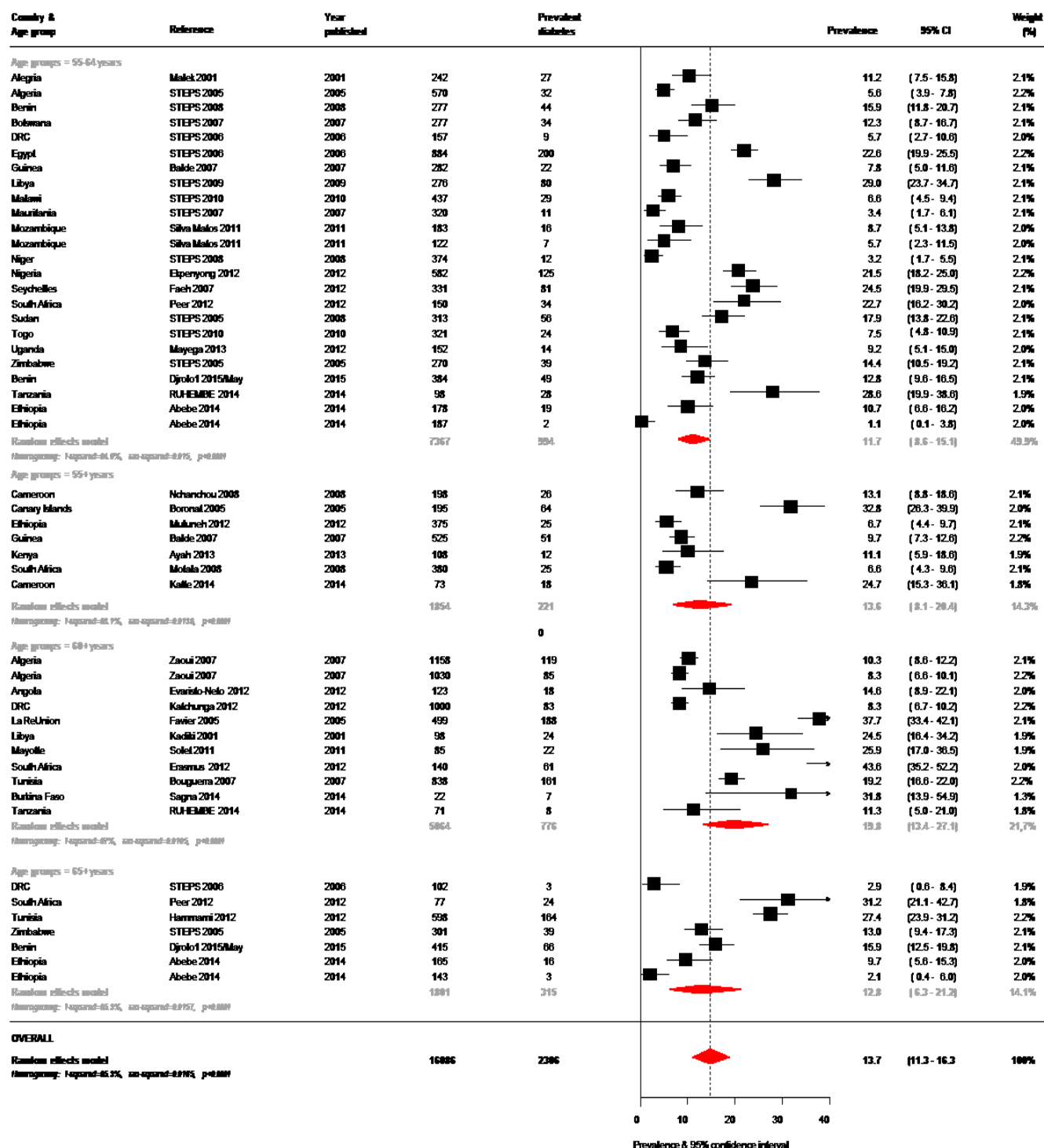
Mauritius	2006	Low	Low	Low	Low	Low	Low	Low	Low	Low	High	Low
Mozambique	Silva-Matos2011	Low	Low	Low	Low	Low	Low	Low	Low	NCS	NCS	Moderate
Niger	2006	Low	High	Low	NCS	Low	Low	Low	Low	Low	NCS	Moderate
Nigeria	Ekpenyong 2012	Low	Low	Low	Low	Low	NCD	NCS	Low	Low	Low	Moderate
Seychelles	Faeh 2007	Low	Low	Low	Low	Low	Low	NCD	Low	Low	NCS	Moderate
South Africa	Motala 2008	Low	Low	Low	Low	Low	low	Low	Low	Low	Low	Low
South Africa	Erasmus 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
South Africa	Peer 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Sudan	2005	Low	NCS	Low	Low	NCS	Low	Low	NCS	Low	Low	Moderate
Tchad	2008	Low	High	NCS	NCS	NCS	Low	NCS	NCS	High	NCS	High
Togo	2010	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Tunisia	Bouguerra 2007	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Tunisia	Hammami 2012	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Uganda	Mayega 2013	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low
Zambia	2008	Low	High	NCS	Low	NCS	Low	Low	High	NCS	NCS	High
Zimbabwe	2005	Low	Low	NCS	Low	NCS	Low	Low	NCS	Low	NCS	Moderate

NCS (Not Clearly Stated)

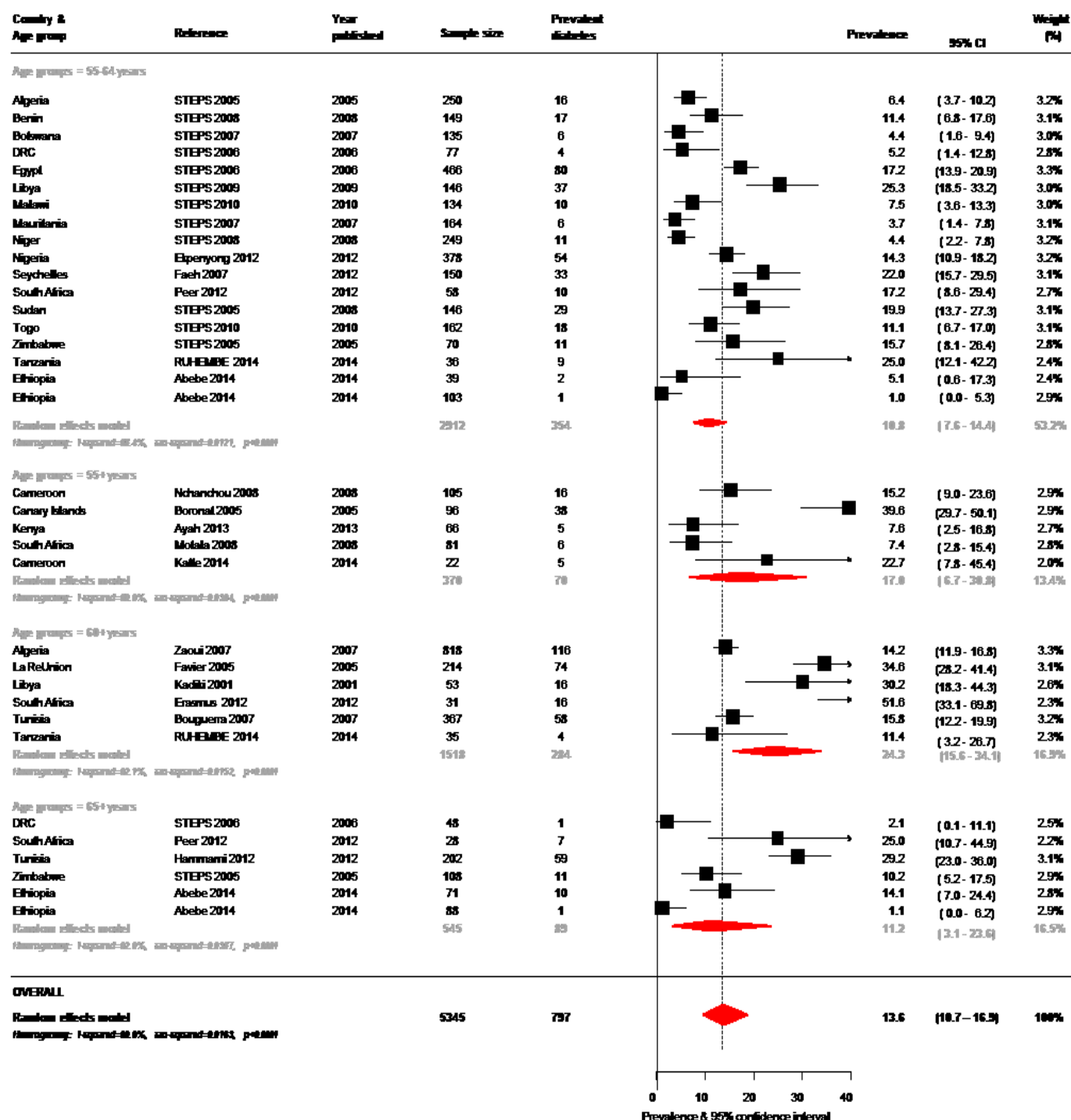
Appendix 8: Assessment of risk bias in included studies



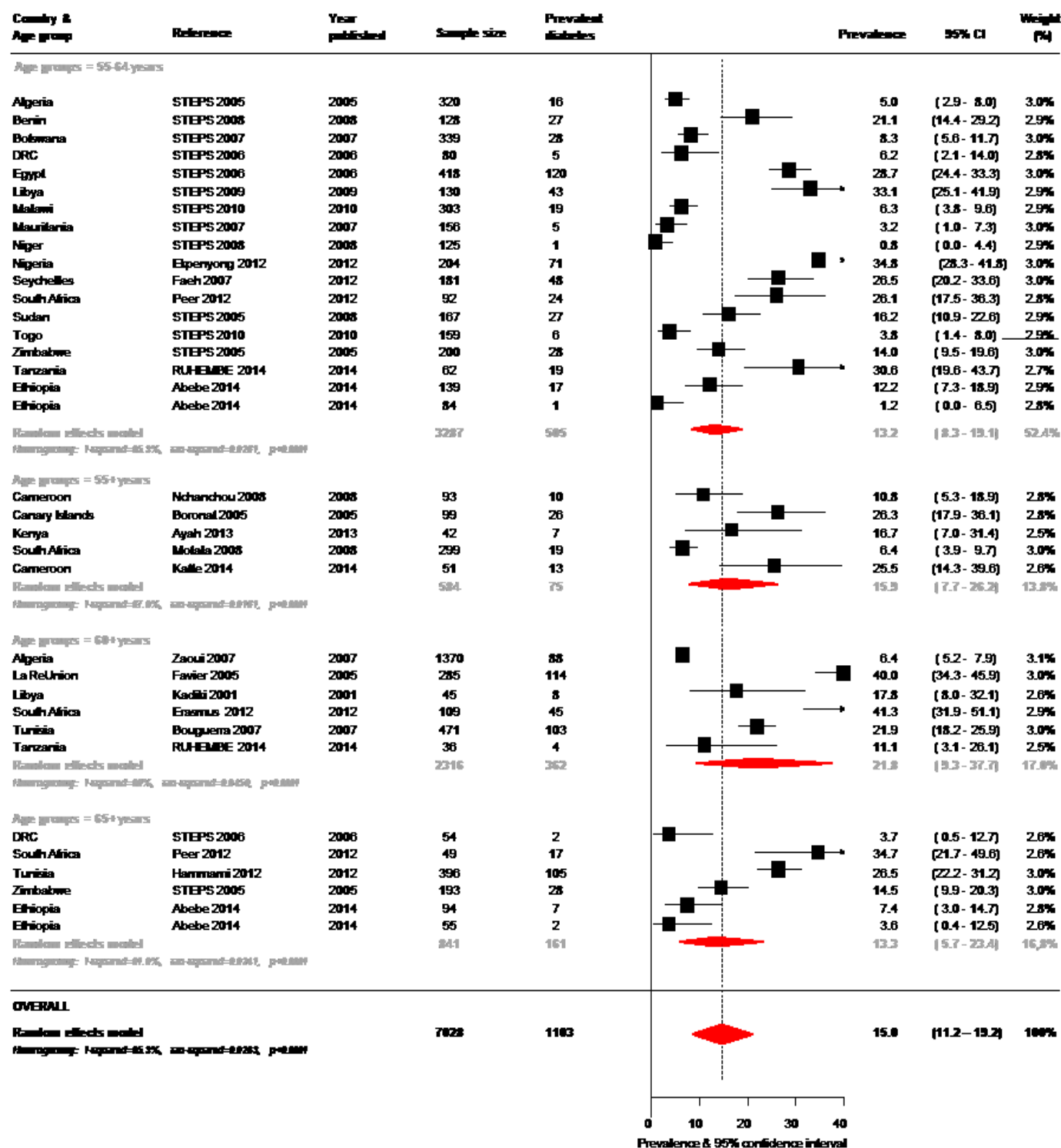
Appendix 9: Forest plots of meta-analysis results, showing men prevalence for type 2 diabetes among older people in Africa.



Appendix 10 Forest plots of meta-analysis results, showing men prevalence for type 2 diabetes among older people in Africa.



Appendix 11 Forest plots of meta-analysis results, showing women prevalence for type 2 diabetes among older people in Africa.



Appendix 12: Excluded Research Studies:

Excluded Research Studies:

The application of the selection criteria resulted in 110 studies excluded from the systematic review. The primary reasons for the exclusion of studies were as follows:

1. The study was not original research (e.g., Narrative reviews, opinion pieces, letters, or any other publications lacking primary data and/or explicit methods descriptions.) (n = 26),
2. The study did not use any of the study designs considered in the review (n = 6)
3. The study did not report measurable data for the outcomes of interest (prevalence) (n = 21)
4. The study did not target the populations of interest (n = 15)
5. The study was not on Type 2 diabetes prevalence (n = 12)
6. The study did not published with review period 2000-2013 (23)
7. The study was not retrieved (n = 2)
8. The study with poor quality rate (n =5)

Table 2 lists the excluded studies and the reason for their exclusion from the systematic review.

Main reason for exclusion:

The study was not original research (N = 26)

-
1. İuf⁹, Â. (2007). Profile of diabetes health care at Benghazi Diabetes Centre, Libyan Arab Jamahiriya. *Eastern Mediterranean he journal*, 13(1), 169.
 2. Motala, A. A., Omar, M. A., & Pirie, F. J. (2003). Epidemiology of type 1 and type 2 diabetes in Africa. *European Journal of Cardiovasc Risk*, 10(2), 77-83.
 3. Whiting, D. R., Hayes, L., & Unwin, N. C. (2003). Challenges to health care for diabetes in Africa. *European Journal of Cardiovascular I* 10(2), 103-110.
 4. Motala, A. A. (2002). Diabetes trends in Africa. *Diabetes/metabolism research and reviews*, 18(S3), S14-S20.

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3. Whiting, D. R., Hayes, L., & Unwin, N. C. (2003). Challenges to health care for diabetes in Africa. *European Journal of Cardiovascular Risk*, 10(2), 103-110.
4. Motala, A. A. (2002). Diabetes trends in Africa. *Diabetes/metabolism research and reviews*, 18(S3), S14-S20.
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The study did not use any of the study designs considered in the review (N=6)

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The study did not report measurable data for the outcomes of interest (prevalence of type 2 DM) (N=21)

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Main reason for exclusion: The study did not target the populations of interest (N = 15)

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Main reason for exclusion: The study was not on type 2 diabetes. (N=12)

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Main reason for exclusion: Studies not published with review period (N=23)

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Main reason for exclusion: study was not retrieved (authors has been contacted for data) (N= 2)

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Main reason for exclusion: study with poor quality rate (N=5)

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Study 2: Supplementary Materials

This appendix formed part of the original submission and has been peer reviewed.

Mahmoud Werfalli, Reshma Kassanje, Sebastiana Kalula, Paul Kowal, Nancy Phaswana-Mafuya & Naomi S. Levitt (2018) Diabetes in South African older adults: prevalence and impact on quality of life and functional disability – as assessed using SAGE Wave 1 data, GlobalHealth Action,

<https://doi.org/10.1080/16549716.2018.1449924>.

Appendix A: Summary statistics for WHOQoL

Table A1. Summary statistics (mean and standard deviation) for WHOQOL (0-100) by covariates and diabetes status

Factor	Category	WHOQoL mean (std deviation)		
		All subjects	Diabetics	Non-diabetics
All subjects		47.4 (12.8)	46.9 (11.3)	47.4 (13.0)
Diabetes	No	47.4 (13.0)		47.4 (13.0)
	Yes	46.9 (11.3)	46.9 (11.3)	
Sex	Female	46.4 (13.0)	46.5 (11.3)	46.4 (13.2)
	Male	48.6 (12.5)	47.9 (11.3)	48.7 (12.6)
Age	50-59 years	47.7 (12.8)	46.5 (11.6)	47.8 (12.9)
	60-69 years	47.2 (12.8)	45.7 (10.9)	47.4 (13.0)
	70+ years	46.7 (12.9)	49.2 (11.3)	46.3 (13.1)
Marital status	Single	44.1 (12.9)	42.7 (11.1)	44.3 (13.1)
	Married/cohabiting	49.5 (12.3)	49.2 (10.9)	49.5 (12.5)
	Separated/divorced	44.2 (14.0)	44.9 (9.6)	44.2 (14.2)
	Widowed	45.2 (12.7)	45.7 (11.4)	45.1 (12.9)
Years of education	0-5 years	44.0 (11.6)	42.6 (9.5)	44.1 (11.8)
	6-12 years	48.4 (12.6)	48.3 (11.4)	48.4 (12.8)
	13+ years	55.7 (11.3)	56.0 (7.7)	55.6 (11.5)
Ethnicity	African/black	44.9 (11.9)	44.5 (11.2)	44.9 (11.9)
	White	58.6 (10.5)	55.7 (6.7)	59.0 (10.9)
	Coloured	50.8 (12.2)	50.8 (11.2)	50.8 (12.3)
	Indian/Asian	49.5 (12.4)	48.7 (10.0)	49.7 (13.1)
Same location	Yes	46.8 (12.0)	47.7 (10.7)	46.8 (12.2)
	No	47.8 (13.5)	45.9 (12.5)	47.9 (13.6)
Past work	Yes	48.2 (12.5)	48.0 (11.4)	48.2 (12.7)
	No	42.3 (13.3)	41.6 (9.1)	42.4 (13.7)
Wealth quintile	poorest	40.2 (11.7)	37.9 (9.4)	40.3 (11.8)
	second	44.1 (11.7)	41.0 (12.3)	44.4 (11.6)
	middle	46.8 (12.3)	48.7 (10.4)	46.7 (12.4)
	fourth	49.5 (11.5)	46.7 (10.5)	49.8 (11.5)
	richest	55.5 (11.5)	52.6 (8.9)	55.9 (11.8)
Tobacco	No	47.4 (12.7)	47.0 (11.4)	47.5 (12.9)
	Yes	47.2 (13.1)	46.9 (10.9)	47.2 (13.2)
Alcohol	No	47.7 (12.5)	47.7 (11.2)	47.7 (12.6)
	Yes	46.3 (13.8)	41.9 (10.8)	46.6 (13.9)
Physical activity	Low	46.0 (12.8)	44.8 (11.2)	46.1 (13.0)
	Moderate	49.8 (12.5)	47.3 (8.9)	50.0 (12.8)
	High	49.8 (12.3)	55.0 (10.6)	49.4 (12.3)
Arthritis	No	48.5 (12.6)	47.3 (11.2)	48.5 (12.7)
	Yes	44.0 (12.8)	46.5 (11.4)	43.5 (13.0)
Stroke	No	47.6 (12.7)	47.3 (11.4)	47.6 (12.9)
	Yes	41.9 (13.8)	42.2 (8.9)	41.8 (14.6)
Angina	No	47.5 (12.8)	47.1 (11.3)	47.6 (12.9)
	Yes	44.2 (13.2)	45.9 (11.3)	43.7 (13.7)
Lung disease	No	47.5 (12.7)	47.5 (11.2)	47.5 (12.9)
	Yes	42.9 (15.2)	41.0 (10.4)	43.6 (16.6)
Asthma	No	47.7 (12.7)	47.6 (11.3)	47.7 (12.9)
	Yes	41.5 (13.1)	40.5 (9.2)	41.7 (13.8)
Depression	No	47.5 (12.8)	47.2 (11.4)	47.6 (12.9)
	Yes	41.4 (12.6)	42.2 (8.7)	41.3 (13.3)
Hypertension	No	47.7 (13.0)	47.3 (10.6)	47.8 (13.1)
	Yes	46.5 (12.5)	46.8 (11.6)	46.4 (12.7)
Cataracts	No	47.3 (12.9)	46.6 (11.2)	47.4 (13.0)
	Yes	49.1 (11.5)	51.3 (9.9)	48.2 (12.0)
# chronic conditions	0	49.4 (12.4)	47.4 (9.4)	49.5 (12.5)
	1	45.6 (12.9)	47.0 (12.6)	45.4 (13.0)
	2	45.6 (13.2)	47.6 (11.3)	45.0 (13.6)
	3+	44.0 (12.5)	47.1 (9.3)	42.9 (13.3)

Appendix B: Summary statistics for WHODAS

Table A2. Summary statistics (mean and standard deviation) for WHODAS (0-36) by covariates and diabetes status

Factor	Category	WHODASi-r mean (std deviation)		
		All subjects	Diabetics	Non-diabetics
All subjects		20.5 (20.3)	25.6 (19.1)	20.2 (20.3)
Diabetes	No	20.2 (20.3)		20.2 (20.3)
	Yes	25.6 (19.1)	25.6 (19.1)	
Sex	Female	22.7 (20.6)	27.2 (18.7)	22.2 (20.7)
	Male	17.8 (19.6)	22.4 (19.5)	17.6 (19.6)
Age	50-59 years	15.8 (16.9)	19.4 (15.8)	15.8 (17.0)
	60-69 years	22.0 (21.2)	29.2 (20.6)	21.3 (21.1)
	70+ years	30.3 (22.8)	29.7 (19.1)	30.3 (23.1)
Marital status	Single	21.1 (18.9)	27.1 (15.7)	20.8 (19.2)
	Married/cohabiting	17.8 (19.1)	23.1 (18.4)	17.4 (19.2)
	Separated/divorced	22.6 (22.8)	12.8 (10.0)	23.4 (23.3)
	Widowed	26.2 (21.8)	29.2 (20.8)	26.0 (21.7)
Years of education	0-5 years	24.3 (21.4)	30.0 (20.9)	24.1 (21.4)
	6-12 years	18.7 (19.0)	22.9 (17.8)	18.3 (19.1)
	13+ years	11.6 (14.2)	27.8 (15.3)	10.5 (13.5)
Ethnicity	African/black	21.8 (20.4)	26.5 (18.5)	21.6 (20.6)
	White	12.6 (15.9)	27.6 (16.3)	10.6 (14.8)
	Coloured	18.9 (19.7)	13.9 (18.5)	19.5 (19.7)
	Indian/Asian	26.7 (22.2)	32.6 (20.9)	25.2 (22.1)
Same location	Yes	20.1 (19.8)	23.5 (17.8)	20.0 (19.9)
	No	21.8 (20.9)	29.2 (21.2)	21.1 (20.7)
Past work	Yes	19.4 (19.4)	23.0 (17.3)	19.0 (19.5)
	No	27.5 (23.8)	39.1 (22.0)	26.9 (23.7)
Wealth quintile	poorest	23.9 (21.5)	35.2 (22.1)	23.8 (21.4)
	second	21.6 (21.5)	29.5 (16.3)	21.0 (21.6)
	middle	21.4 (20.1)	22.3 (18.5)	21.3 (20.3)
	fourth	20.0 (18.8)	24.1 (19.2)	19.5 (18.7)
	richest	16.2 (18.7)	23.2 (18.3)	15.3 (18.6)
Tobacco	No	20.9 (20.4)	27.5 (18.1)	20.1 (20.5)
	Yes	20.2 (20.1)	18.4 (21.0)	20.3 (20.0)
Alcohol	No	20.7 (20.4)	25.2 (18.9)	20.2 (20.5)
	Yes	20.6 (20.1)	28.3 (20.1)	20.2 (20.0)
Physical activity	Low	24.7 (22.2)	26.2 (20.1)	24.5 (22.4)
	Moderate	16.6 (16.7)	27.5 (13.7)	15.5 (16.6)
	High	13.4 (14.3)	17.5 (14.0)	13.1 (14.3)
Arthritis	No	17.4 (18.9)	21.4 (17.7)	17.2 (19.0)
	Yes	30.5 (21.1)	30.7 (19.4)	30.4 (21.4)
Stroke	No	20.0 (19.8)	24.5 (18.4)	19.5 (19.9)
	Yes	37.5 (23.6)	39.6 (22.8)	37.0 (23.8)
Angina	No	20.2 (20.1)	25.0 (18.5)	19.8 (20.2)
	Yes	28.9 (21.1)	30.1 (22.3)	28.5 (20.8)
Lung disease	No	20.5 (20.2)	24.6 (18.8)	20.1 (20.3)
	Yes	27.9 (20.7)	36.5 (18.7)	24.8 (20.7)
Asthma	No	20.2 (20.2)	25.5 (19.0)	19.7 (20.3)
	Yes	29.4 (19.5)	26.4 (20.3)	30.1 (19.4)
Depression	No	20.4 (20.3)	24.8 (18.9)	20.0 (20.4)
	Yes	29.9 (18.0)	39.6 (17.2)	27.8 (17.6)
Hypertension	No	18.3 (19.6)	21.4 (18.7)	18.2 (19.6)
	Yes	26.0 (20.9)	27.4 (19.0)	25.6 (21.3)
Cataracts	No	20.4 (20.3)	25.3 (18.9)	19.9 (20.4)
	Yes	25.4 (18.5)	23.2 (18.3)	26.2 (18.6)
# chronic conditions	0	14.9 (18.0)	20.8 (16.1)	14.7 (18.0)
	1	23.9 (20.2)	23.5 (19.0)	23.9 (20.3)
	2	28.6 (21.3)	25.3 (19.2)	29.6 (21.8)
	3+	33.5 (20.3)	30.8 (18.7)	34.4 (20.8)

Appendix C: Distribution of WHOQoL (0-100 scale)

Figure C1. Histogram of WHOQoL scores, with superimposed fitted normal distribution

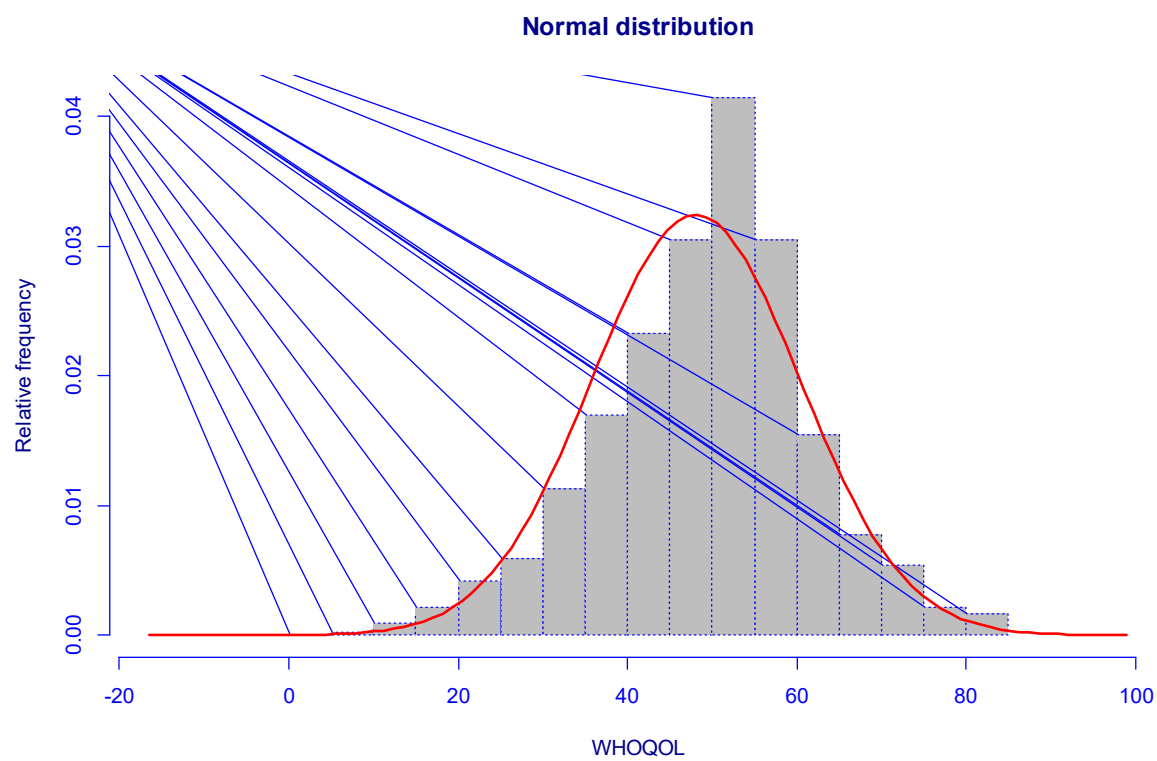
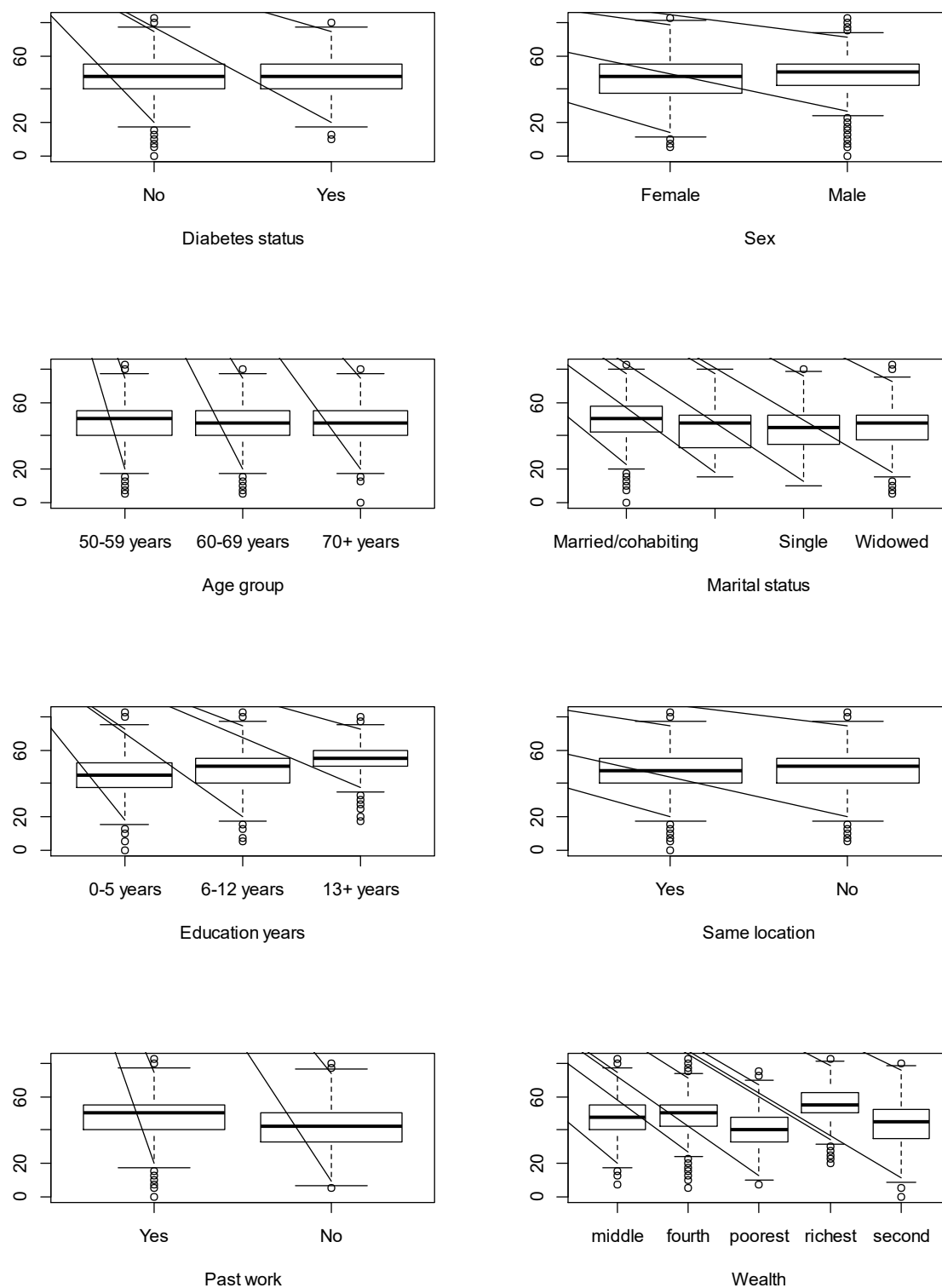
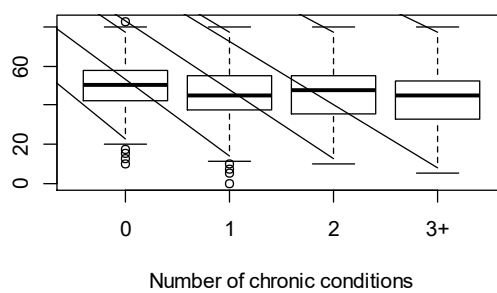
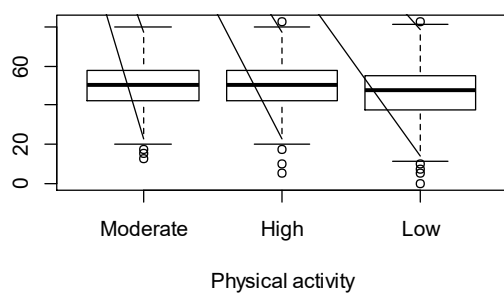
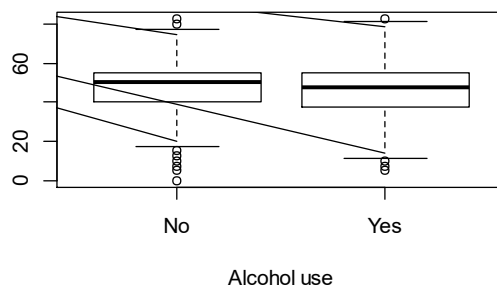


Figure C2. Box-and whisker plots of WHOQoL scores (0-100 scale), stratified by diabetes status, sociodemographic factors, health risk behaviours, and number of chronic conditions





Appendix D: Distribution of WHODAS (0-36 scale)

Figure D1. Histogram of WHODAS scores, with superimposed fitted negative binomial distribution and zero-inflated negative binomial distribution

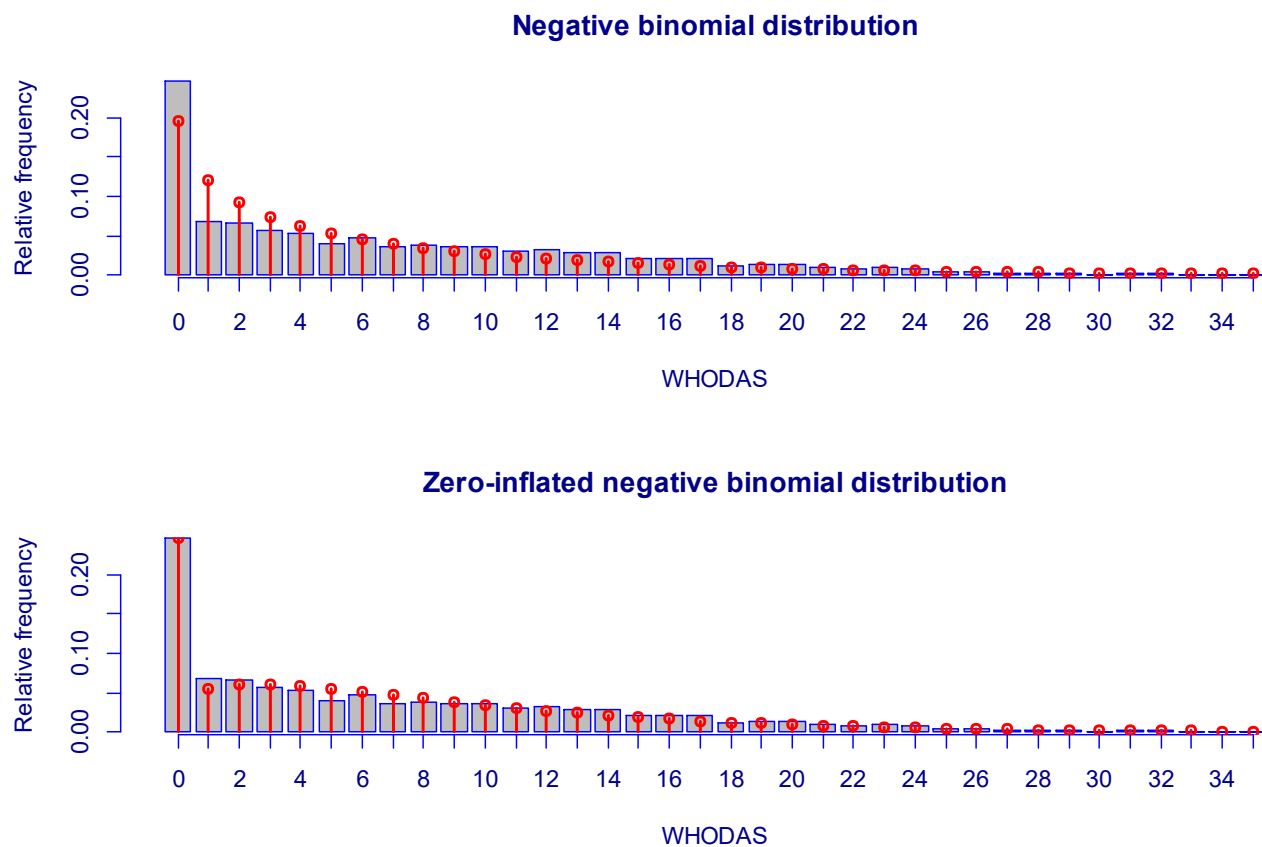
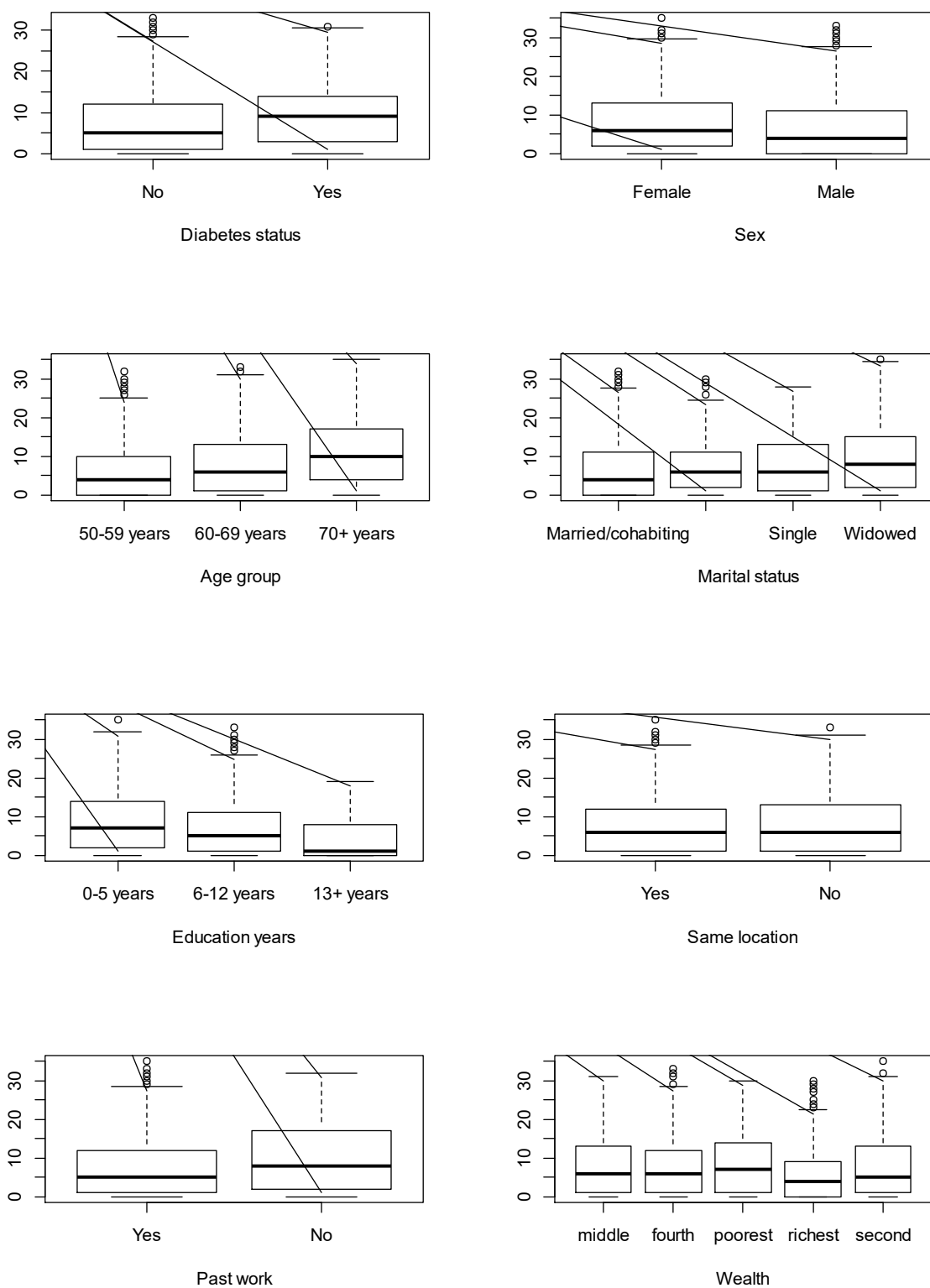
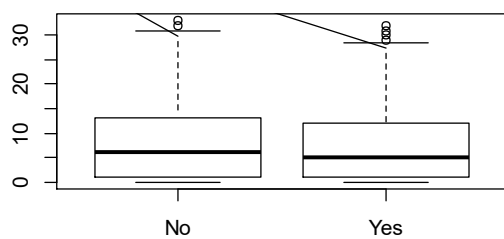
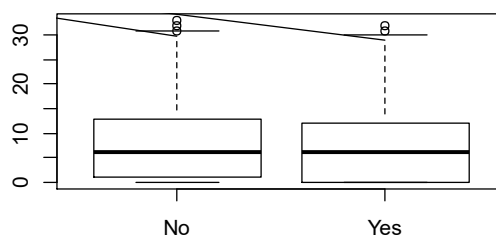


Figure D2. Box-and whisker plots of WHODAS scores (0-36 scale), stratified by diabetes status, sociodemographic factors, health risk behaviours, and number of chronic conditions

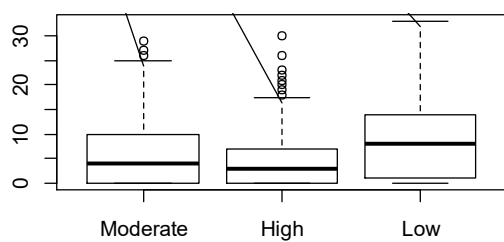




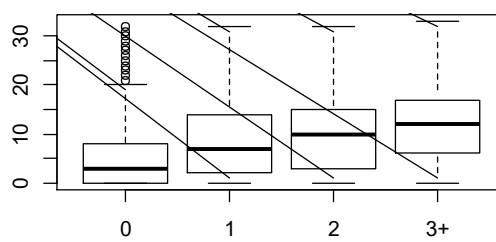
Tobacco use



Alcohol use



Physical activity



Number of chronic conditions

Appendix E: Methodology

Data were analysed using R (version 3.1.3) and Stata (Stata/MP 13.1). The sampling design and probability weights were taken into account using R's 'survey' package and Stata's suite of 'svy' commands.

We assessed the association of diabetes and other factors with WHOQOL and WHODAS, as well as the moderation effects of diabetes, using generalised linear models. WHOQOL and WHODAS were considered in turn.

For WHOQOL, a standard multiple linear regression model was used. Estimated effect sizes captured the absolute change in the mean WHOQOL score as a factor changed from the reference category to the indicated category, holding all else equal – termed additive effects in the text. These impacts were allowed to differ by diabetes status. Initially diabetes was allowed to moderate all effects (see Appendix F for the full model), but in the main text a trimmed model is presented, where the moderation effects included are those where the initial model suggested evidence of moderation (p-values <0.1).

For WHODAS, a zero-inflated negative binomial regression model was used to describe disability on a 0-36 count scale, with higher values indicating greater disability level. Within this framework, disability scores are split into two distinct groups. Firstly, there are the excess of 0 scores, corresponding to no disability, that result in a peak of scores at 0. This clustering of 0 values needs to be explicitly accounted for in the statistical model. Secondly, there are the remaining scores which range from 0 upwards and follow a standard statistical distribution (a negative-binomial distribution in this case). Two sets of effect sizes are thus reported: Odds ratios (ORs) for the excess 0 scores, and multiplicative effects, a term used here to indicate the ratio change in the mean of the remaining scores. In the initial model, each factor was allowed to (independently) impact the OR, and the multiplicative effect allowed to differ by diabetes status (see Appendix G for the full model). In the main text, a trimmed model is presented: the moderation effects included are those where the initial model suggested evidence of moderation (p-values <0.1); an OR was included for a factor only where the initial model suggested evidence for this (p-values <0.1). Changes in factors that are associated with a decrease in disability can be identified by an OR greater than 1 (i.e. more scores are clustered at 0) and a multiplicative effect less than 1 (i.e. after accounting for and removing the excess of 0 scores, the average of the remaining scores is also smaller). Conversely, when the OR is less than 1 and multiplicative effect greater than 1, there are fewer excess 0 scores and the remaining scores are centered around a larger value, and there is greater disability.

Model fit was assessed using residual plots (not shown here) and comparisons of observed and model-fitted means (see Appendix H for some outputs).

Confidence intervals (CIs) for estimated model parameters are based on Wald-type intervals. The significance of terms was assessed using Wald tests, where small p-values suggest evidence of relationships (or rather evidence against the hypotheses of no relationships).

List-wise deletion of observations with missing values resulted in 2848 observations for WHOQOL and 2866 observations for WHODAS. The most common sources of missing values were: 570 for education, 492 for place of residence and 123 for physical activity.

Estimated effect sizes and CIs are reported in the results, as well as two key p-values for each factor: (1) The p-value for 'factor' relates to testing whether that factor is related to well-being (WHOQOL or WHODAS) in any way. (2) The p-value for the 'moderation effect' relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without.

Because testing for moderation is of interest, the dataset was not stratified into individuals with diabetes and those without, but rather all data used in the model.

Appendix F: Untrimmed regression model for WHOQoL

Table F1: Association of diabetes, sociodemographic characteristics, self-reported health behaviours and comorbidities with WHOQOL (0-100) – original model before removing terms

		Additive effect / regression coefficient (95% CI)		P-value ¹	
Factor	Category	Non-diabetic group	Diabetic group	Factor	Moderation effect
Diabetes	No (ref)		4.6 (-1.4;10.7)	<0.001	N/A
	Yes	-4.6 (-10.7;1.4)			
Sex	Female (ref)			0.086	0.373
	Male	-1.6 (-3.0;-0.2)	-0.2 (-3.0;2.7)		
Age	50-59 years (ref)			0.177	0.975
	60-69 years	1.7 (0.3;3.2)	1.3 (-2.4;5.0)		
	70+ years	1.4 (-0.4;3.3)	1.1 (-2.9;5.1)		
Marital status	Single	-2.6 (-4.9;-0.3)	-2.4 (-6.2;1.4)	0.052	0.978
	Married/cohabiting (ref)				
	Separated/divorced	-1.2 (-4.3;1.9)	-1.1 (-6.8;4.5)		
	Widowed	-2.6 (-4.3;-0.9)	-1.7 (-5.2;1.7)		
Years of education	0-5 years (ref)			0.001	0.102
	6-12 years	2.1 (0.4;3.8)	2.7 (-0.7;6.1)		
	13+ years	4.4 (1.2;7.6)	12.5 (5.4;19.7)		
Same location	Yes (ref)			0.704	0.411
	No	0.4 (-1.2;2.0)	-1.1 (-4.3;2.1)		
Past work	Yes (ref)			0.003	0.086
	No	-4.3 (-6.7;-1.9)	-0.5 (-4.3;3.3)		
Wealth quintile	poorest	-6.8 (-9.2;-4.5)	-9.3 (-14.3;-4.3)	<0.001	0.075
	second	-2.8 (-5.2;-0.3)	-5.8 (-12.0;0.5)		
	middle (ref)				
	fourth	0.6 (-1.5;2.6)	-3.4 (-8.0;1.2)		
	richest	7.0 (4.3;9.7)	0.4 (-3.4;4.2)		
Tobacco	No (ref)			0.228	0.138
	Yes	0.2 (-1.6;2.0)	3.4 (-0.5;7.3)		
Alcohol	No (ref)			0.14	0.924
	Yes	-1.6 (-3.6;0.3)	-1.8 (-4.8;1.2)		
Physical activity	Low	-3.3 (-5.3;-1.3)	-1.2 (-4.6;2.3)	<0.001	0.023
	Moderate (ref)				
	High	-0.1 (-2.2;2.0)	8.0 (2.7;13.4)		
# chronic conditions	0 (ref)			<0.001	0.001
	1	-4.7 (-6.2;-3.1)	-2.2 (-5.7;1.4)		
	2	-6.6 (-8.5;-4.8)	-0.4 (-4.4;3.6)		
	3+	-6.9 (-10.0;-3.8)	1.6 (-2.3;5.5)		

¹ The p-value for 'factor' relates to testing whether that factor is related to well-being in any way. The p-value for the 'moderation effect' relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without.

Appendix G: Untrimmed regression model for WHODAS

Table G1: Association of diabetes, sociodemographic characteristics, self-reported health behaviours and comorbidities with WHODAS (0-36) – original model before removing terms

Factor	Category	Effect sizes (95% CI)			P-value ¹	
		Odds Ratio (OR)	Multiplicative effect / exponentiated regression coefficient		Factor	Moderation effect
			Non-diabetic group	Diabetic group		
Diabetes	No (ref)	1.9 (0.6,5.5)		0.6 (0.4,0.8)	<0.001	N/A
	Yes	0.5 (0.2,1.6)	1.7 (1.2,2.5)			
Sex	Female (ref)				0.119	0.031
	Male	1.1 (0.8,1.6)	1.0 (0.9,1.2)	0.7 (0.5,1.0)		
Age	50-59 years (ref)				<0.001	0.846
	60-69 years	0.8 (0.5,1.1)	1.1 (0.9,1.2)	1.1 (0.8,1.5)		
	70+ years	0.6 (0.3,0.9)	1.4 (1.2,1.5)	1.5 (1.1,2.0)		
Marital status	Single	0.5 (0.3,0.9)	1.1 (0.9,1.3)	1.0 (0.8,1.4)	0.015	0.047
	Married/cohabiting (ref)					
	Separated/divorced	0.5 (0.2,1.2)	1.0 (0.9,1.2)	0.6 (0.3,0.9)		
	Widowed	0.5 (0.3,0.9)	1.1 (0.9,1.2)	0.9 (0.7,1.2)		
Years of education	0-5 years (ref)				<0.001	0.000
	6-12 years	2.0 (1.4,2.9)	0.9 (0.8,1.0)	0.9 (0.7,1.1)		
	13+ years	3.2 (1.8,5.9)	0.6 (0.5,0.8)	1.5 (1.0,2.3)		
Same location	Yes (ref)				0.005	0.121
	No	1.3 (0.9,1.8)	1.1 (1.0,1.3)	1.4 (1.1,1.8)		
Past work	Yes (ref)				0.004	0.183
	No	1.0 (0.5,1.9)	1.3 (1.0,1.5)	1.5 (1.2,2.1)		
Wealth quintile	poorest	1.3 (0.7,2.2)	1.2 (1.0,1.4)	1.3 (0.9,2.0)	0.087	0.870
	second	1.1 (0.7,1.9)	1.1 (1.0,1.2)	1.3 (0.9,1.9)		
	middle (ref)					
	fourth	0.6 (0.3,1.0)	1.0 (0.8,1.1)	1.0 (0.7,1.4)		
	richest	0.9 (0.5,1.5)	0.9 (0.8,1.1)	1.0 (0.7,1.4)		
Tobacco	No (ref)				0.361	0.077
	Yes	1.0 (0.7,1.5)	1.0 (0.9,1.2)	0.7 (0.5,1.0)		
Alcohol	No (ref)				0.033	0.537
	Yes	1.0 (0.6,1.5)	1.2 (1.0,1.4)	1.4 (0.9,2.0)		
Physical activity	Low	1.0 (0.6,1.7)	1.4 (1.2,1.6)	0.9 (0.7,1.1)	<0.001	0.002
	Moderate (ref)					
	High	0.7 (0.4,1.3)	0.8 (0.7,1.0)	0.7 (0.5,1.0)		
# chronic conditions	0 (ref)				<0.001	0.003
	1	0.4 (0.2,0.5)	1.3 (1.2,1.5)	0.9 (0.6,1.1)		
	2	0.2 (0.1,0.3)	1.7 (1.5,1.9)	1.0 (0.8,1.4)		
	3+	0.1 (0.0,0.3)	1.7 (1.4,2.0)	1.0 (0.7,1.4)		

¹ The p-value for 'factor' relates to testing whether that factor is related to well-being in any way. The p-value for the 'moderation effect' relates to testing whether diabetes moderates the relationship between that factor and the well-being score – i.e. whether the relationship is different between individuals with diabetes and those without.

Appendix H: Observed versus model fitted average scores

Table H1: Observed versus model-fitted (trimmed model) mean WHOQoL (0-100 scale) scores

Factor	Category	Observed mean	Fitted mean
Diabetic	No	48.13	47.05
	Yes	46.38	47.70
Sex	Female	47.40	46.62
	Male	48.83	47.86
Age	50-59 years	48.23	46.98
	60-69 years	48.30	47.58
	70+ years	47.03	46.70
Marital	Married/cohabiting	49.80	49.12
	Separated/divorced	46.24	46.49
	Single	45.99	44.19
	Widowed	46.11	45.18
Education years	0-5 years	45.29	44.15
	6-12 years	49.47	48.77
	13+ years	55.52	55.52
Same Location	Yes	47.63	46.75
	No	48.78	48.00
Tobacco use	No	48.16	47.42
	Yes	47.61	46.55
Alcohol use	No	48.12	47.51
	Yes	47.56	46.05
Past work	Yes	48.67	47.82
	No	43.29	42.42
Wealth	poorest	41.71	40.28
	second	45.57	44.29
	middle	47.72	47.22
	fourth	48.92	48.00
	richest	55.45	55.27
Physical activity	Low	46.72	45.81
	Moderate	50.04	49.67
	High	50.12	49.16
Number of chronic conditions	0	50.04	49.18
	1	46.60	45.37
	2	45.27	44.65
	3+	43.88	44.43

Table H2: Observed versus model-fitted (trimmed model) mean WHODAS (0-36 scale) scores

Factor	Category	Observed mean	Fitted mean
Diabetic	No	7.26	7.71
	Yes	9.22	8.30
Sex	Female	8.06	8.35
	Male	6.34	6.87
Age	50-59 years	5.61	6.07
	60-69 years	7.86	7.73
	70+ years	10.77	10.87
Marital	Married/cohabiting	6.32	6.56
	Separated/divorced	8.12	7.47
	Single	7.42	8.21
	Widowed	9.36	9.72
Education years	0-5 years	8.75	9.14
	6-12 years	6.71	6.89
	13+ years	4.14	4.43
Same Location	Yes	7.23	7.64
	No	7.80	8.06
Tobacco use	No	7.52	7.59
	Yes	7.41	8.41
Alcohol use	No	7.45	7.52
	Yes	7.41	8.41
Past work	Yes	6.96	7.35
	No	9.90	10.52
Wealth	poorest	8.52	8.84
	second	7.71	8.30
	middle	7.63	7.94
	fourth	7.08	7.55
	richest	5.73	6.26
Physical activity	Low	8.88	9.16
	Moderate	5.99	6.45
	High	4.81	4.84
Number of chronic conditions	0	5.35	5.55
	1	8.59	8.84
	2	10.30	11.67
	3+	12.06	11.83

Study 3: Supplementary Materials

This appendix formed part of the original submission and has been peer reviewed



Appendix A Questionnaire Survey (Translated Version from English to Afrikaans)

Chronic Disease Initiative in Africa (CDIA) /UCT

Title of study: Development of a self-management programme for older people with type 2 diabetes attending community health centers in Cape Town metropole

Questionnaire Survey

Supervisor: Professor Naomi (Dinky) Levitt

Co – Supervisor: Dr Sebastiana Kalula

Student: Mahmoud Werfalli

Community Health Centre

Telephone number:

Name:

Record No:

ID No:

Interviewer No:

A. Can you please give me information about yourself (Choose the answers that describes you best) *Kan u/ju asseblief vir my informasie gee oor uself/jouself. (Kies die antwoorde wat u/jou die beste beskryf)*

Q1. In what year were you born?

Y	Y	Y	Y	M	M	D	D

In watter jaar is u/jy gebore?

J	J	J	J	M	M	D	D

Q2. Gender

☐ Male ☐ Female

Geslag

☐ *Manlik* ☐ *Vroulik*

Q3. What is your current marital status?

☐ single ☐ married ☐ divorced ☐ widow/widower ☐

Wat is u/jou huwelikstatus op die oomblik?

☐ *Enkel* ☐ *Getroud* ☐ *Geskei* ☐ *Weduwee* ☐ *Geskei*

Q4. What is the highest level of education that you completed

☐ none ☐ lower than grade6(Standard 4) ☐ grade 6(Std4) ☐ grade9(Std7)
☐ grade 10(Std8) ☐ grade 11(Std9) ☐ grade 12(Std10) ☐ college ☐ university

Wat is die hoogste vlak van opvoeding wat u/jy voltooi het?

☐ *Nie opvoeding voltooi nie* ☐ *opvoeding tot by graad 6* ☐ *graad 6* ☐ *graad 9* ☐ *graad 10*
☐ *graad11Universiteit* ☐ *ollege k* ☐ *12 adgra* ☐

Q5. Are you currently employed with an income

☐ yes ☐ no

Het u/jy huidiglik n werk met n inkomste?

☐ *Ja* ☐ *Nee*

Q6a.If yes, are you working

☐ full time ☐ part time

Indien ja, werk u/jy

☐ *Voltyds* ☐ *Deeltyds*

Q6b. If no, are you

☐ unemployed(but physically able to work)

☐ not able to work because of e.g health problems ☐ receiving a state grant (e. g pension)

Indien nee, is u /jy?

☐ *Werkloos (maar liggaamlik instaat om te werk)*

☐ *Nie instaat om te werk as gevolg van (a.g.v) gesondheids-probleme* ☐ *ontvang a toelaag van die staat (b.v. pension)*

Q7. With who are you sharing a house

☐ spouse ☐ family member ☐ friend ☐ living alone ☐
more than one person in the house

Wie deel n huis met u/jou?

☐ *Eggenoot* ☐ *Familie lid* ☐ *Vriend/Vriendin* ☐ *Bly alleen* ☐ *Meer as een person in huis*

Q8. What is your monthly income

☐ <R 500 ☐ R 500 - R1499 ☐ R1500 - R2999 ☐ >R 3000

Wat is u/jou inkomste per maand?

☐ <R 500 ☐ R 500 - R1499 ☐ R1500 - R2999 ☐ >R 3000

B. I am now going to ask you questions about your diabetes/ sugar illness

B. *Ek gaan u/jou nou vrae vra oor u suikersiekte/diabetes*

Q1. How long have you had diabetes/ sugar illness

☐ less than 5 years ☐ 5-10 years ☐ 11-16 years ☐ > 17 years

Hoeveel jaar het u/jy nou suikersiekte/diabetes?

☐ *Minder as 5 jaar* ☐ *5-10 jaar* ☐ *11-16 jaar* ☐ *>17 jaar*

Q2. Are you taking any medication for the sugar illness/diabetes that has been prescribed by a doctor or nursing sister

☐ yes ☐ no

Neem u/jy medisyne vir die suikersiekte/diabetes wat deur n dokter of verpleegster voorgeskryf is?

☐ *Ja* ☐ *Nee*

Q3.if yes, please indicate the type of treatment

☐ insulin injections ☐ tablets ☐ both ☐ no medication
☐ I don't know

Indien ja, kies die tipe behandeling?

☐ *Insulien inspuitings* ☐ *Pille* ☐ *Beide* ☐ *Geen medikasie* ☐ *ek weet nie*

Q4. are you taking any other medication for other chronic illnesses

- ☐ high blood pressure ☐ heart disease ☐ traditional medicine ☐ other (.....)
☐ I don't know

Ontvang u/jy medisyne vir enige ander kroniese siektes

- ☐ Hoë Bloeddruk ☐ Hartsiekte ☐ Tradisionele medikasie ☐ ander (.....)
☐ Ek weet nie

Q5a. did you ever receive any advise from a doctor, dietician or nurse on how to live with diabetes/ sugar illness

- ☐ yes ☐ no

(a) Het u/jy al ooit enige raad/advies ontvang vanaf 'n dokter, diëtikus of verpleegster, oor hoe om te lewe met suikersiekte/diabetes?

- ☐ Ja ☐ Nee

Q5b. or from a health promoter or community health care worker

- ☐ yes ☐ no

Of vanaf 'n gesondheids promotor of 'n gemeenskaps gesondheids werker?

- ☐ Ja ☐ Nee

Did you ever experience any of the following problems that is associated with diabetes/ sugar illness (name the following and tick the appropriate boxes)

Q6

- ☐ low blood sugar (<4mmol/L) ☐ High blood sugar(>10 mmol/L)
☐ Heart problems ☐ sexual problems/dysfunction ☐ damage to the back of the eye
☐ damage to the nerves (e.g numbness, pins and needles in the hands and feet or sores on the feet)
☐ Kidney problems ☐ none of the above
☐ I don't know

*Het u al enige van die volgende probleme, wat met suikersiekte/diabetes geassosieer word eervaar?
(Noem die volgende en merk die wat pas)*

- ☐ Lae bloedsuiker (< 4 mmol/L) ☐ Hoë bloedsuiker (>10 mmol/L)
☐ Hart problem/siekte ☐ Seksuele probleme ☐ Beskadiging in die agterkant van die oog
☐ Beskadiging van die sensuïes (b.v gevoelloosheid, prikkel gevoel in die hande en voete, of sere op die voete)
☐ Nier problem ☐ Niks van bogenoemde
☐ Ek weet nie

Q7. have you been admitted to hospital for diabetes/ sugar illness in the last 12 months

☐ Yes ☐ No

Was u/jy in die laaste 12 maande opgeneem in die hospital vir u/jou suikersiekte/diabetes

☐ Ja ☐ Nee

Q8. what is your current status in terms of smoking

☐ currently smoking ☐ previous smoker ☐ never smoked

Wat is u/jou huidige posisie ten opsigte van die rook van sigarette?

☐ Rook tans ☐ het voorheen gerook ☐ nog nooit gerook

Q9. If you are smoking, how long have you been smoking

☐ Less than 2 years ☐ 2–3 years ☐ 3–4 years ☐ 4–5 years ☐ 5 or more years

Indien u/jy well rook, hoelank rook u?

☐ Minder as 2 jaar ☐ 2–3 jaar ☐ 3–4 jaar ☐ 4–5 jaar ☐ 5 jaar of meer

Q10. Did your doctor, nurse or health care worker ever gave you counselling to stop smoking

☐ Yes ☐ No ☐ Not applicable

Het u/jou dokter, verpleegster, of gesondheids werker u/jou al ooit berading gegee om op te hou rook?

☐ Ja ☐ Nee ☐ Nie van toepassing

I am now going to ask you questions regarding your lifestyle and how you manage your sugar illness/ diabetes

Ek gaan u/jou nou vrae vra met betrekking tot u/jou leefwyse en hoe u/jy die suikersiekte/diabetes beheer?

Q1. In the last 7 days how often did you go for a walk out of the house or in the yard? Example doing exercise just for fun, walked to work, took the dog for a walk, walked to the shop ect

☐ Never (0 days) ☐ Seldom (1 or 2 days) ☐ Sometimes (3 or 4 days) ☐ Often (5–7 days)

In die afgelope 7 dae hoe gereeld het u/jy 'n end gestap buite die huis of in die agterplaas? Byvoorbeeld Oefening gedoen net vir pret, werk toe geloop, die hond vir 'n stappie geneem, na die winkiel toe geloop ens)

☐ Nooit (0 dae) ☐ Weinig (1 of 2 dae) ☐ Somtyds (3 of 4) ☐ Gereeld (5–7 dae)

Q2 in the last 7 days how often did you participate in a sitting activity like reading, watching television or doing needle work

☐ Never (0 days) ☐ Seldom (1 or 2 days) ☐ Sometimes (3 or 4 days) ☐ Often (5–7 days)

In die afgelope 7 dae hoe gereeld het u/jy deelgeneem in 'n sittende aktiwiteit soos lees, televisie kyk, of handwerk doen?

☐ Nooit (0 dae) ☐ Weinig (1 of 2 dae) ☐ Somtyds (3 of 4 dae) ☐ Gereeld (5–7 dae)

Q3a. in the past did you ever receive any information from a doctor or nurse regarding physical activity and sugar illness/diabetes

☐ Yes ☐ No

(a) Het u/jy al enige advies/informasie in die verlede ontvang, vanaf 'n dokter of verpleegster met betrekking tot, fisiese aktiwiteite/oefeninge en suikersiekte/diabetes

☐ Ja ☐ Nee

Q3b. or from a health promoter or community health care worker

☐ Yes ☐ No

(b) Of vanaf 'n gesondheids promotor of gemeenskaps gesondheids werker ?

☐ Ja ☐ Nee

Q4. Do you sometimes forget to take your medication

☐ Yes ☐ No

Het u/jy al somtyds vergeet om u/jou medikasie te neem vir suikersiekte/diabetes?

☐ Ja ☐ Nee

Q5a. do you need help with giving/ injecting/ administering your insulin

☐ Yes ☐ No

Benodig u/jy hulp met die toediening van u/jou insulien inspuitings?

☐ Ja ☐ Nee

Q5b. if yes, what do you need help with

☐ Drawing up ☐ Injecting ☐ others (specify) ☐ none needed

Indien Ja, watter tipe hulp benodig u/jy?

☐ Optrek van die oplossing ☐ Toediening van die inspuiting ☐ Ander (Verduidelik.....)
☐ Geen hulp word benodig

Q6. did you ever stopped taking your medication without your doctors permission because it made you feel
unwell

☐ Regularly ☐ Sometimes ☐ Rarely ☐ No

*Het u/jy al ooit sonder die dokter se toestemming opgehou om u/jou medikasie te neem, , omdat dit u/jou laat
sleg voel?*

☐ Gereeld ☐ Somtye ☐ Weinig ☐ Nee

Q if you travel or leave the house do you ever forget to take your medication for diabetes/ sugar illness with
you

☐ Yes ☐ No ☐ some times

Indien u/jy op reis gaan of die huis verlaat, vergeet u/jy om u/jou medikasie vir suikersiekte/diabetes te neem?

☐ Ja ☐ Nee

Q8. When you feel your sugar illness / diabetes is under control, do you stop your medication

☐ Yes ☐ No ☐ sometimes

Wanneer u/jy voel dat die suikersiekte/diabetes onder beheer is, stop u/jy die medikasie ?

☐ Ja ☐ Nee ☐ Somtye

Q9. A lot of people think to drink medication every day is very difficult. Do you find it difficult to stick to your sugar illness/ diabetes treatment plan

☐ Yes ☐ No ☐ not sure

Baie mense voel om hulle medikasie elke dag te drink is baie moeilik. Vind u/jy dit ooit moeilik om te hou by u/jou suikersiekte/diabetes behandelings plan?

☐ Ja ☐ Nee ☐ Nie Seker nie

Q10. How often do you find it difficult to remember to take all your medication

☐ Never/rarely ☐ occasionally ☐ All the time

Hoe gereeld vind u/jy dit moeilik om te othou om al u/jou medisyne te neem?

☐ Nooit/Weinig ☐ Somtye ☐ Altyd

Do you follow a diabetes/ sugar illness eating plan

Q11.

☐ Yes ☐ No

Volg u/jy n suikersiekte/diabetes eetplan

☐ Ja ☐ Nee

Q12. did you ever receive any advice/information from a doctor, dietician or nurse regarding what you must eat for your diabetes/ sugar illness

☐ Yes ☐ No

Het u/jy al ooit advies/informasie ontvang vanaf n dokter, dietkundige of n verpleegster, oor wat u/jy moet eet, as gevolg van (a.g.v.) die suikersiekte/diabetes?

☐ Ja ☐ Nee

Q13a. Do you ever test your blood sugar

☐ Yes ☐ No

Toets u/jy ooit u/jy bloed suiker?

☐ Ja ☐ Nee

Q13b if yes, how often

☐ Once a day ☐ 3 or 4 times a day ☐ 1 or 2 times a week ☐ occasionally as needed

Indien ja, hoe gereeld?

☐ Eenkeer per Dag ☐ 3 of 4 keer per dag ☐ 1 of 2 keer per week ☐ Somtye soos benodig

Q13c. Who test your blood sugar

☐ Myself ☐ Family ☐ health care Workers ☐ other

Wie doen dit?

☐ Self ☐ Familie ☐ Gesondheids werker ☐ Ander

Q14. When last did you test your urine

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Wanneer laas was u/jou urine getoets?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

Q15 when last was your blood pressure tested

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Wanneer laas was u/jou bloeddruk /geneem?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

Q16. When last was your cholesterol(fat in the blood) tested

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Was laas was u/jou bloedvet(cholesterol) getoets?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

Q17 when did a doctor or nurse looked at the back of your eye or took a photo of the back of your eye

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Wanneer het n dokter/verpleegster gekyk na die agterkant van u/jou oë of n foto geneem van die agterkant van u/jou oë?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

Q18. When last was your feet examined

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Wanneer laas was u/jou voete ondersoek?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

Q19 when last dis you have a doctor's visit or attended a doctor's appointment

☐ One month ago ☐ Six months ago ☐ One year ago ☐ Two years ago ☐ Not done at all

Wanneer laas het u/jy n dokter's besoek gehad?

☐ Een maand gelede ☐ Ses maande gelede ☐ Een jaar gelede ☐ Twee jaar gelede ☐ Nog nie gedoen nie

D. I am now going to ask you questions about diabetes/ sugar illness (choose the most appropriate answer(s) for the following stat

Ek gaan u/jou nou vrae vra oor suikersiekte/diabetes

(Kies die mees gepaste antwoord(e) vir die volgende verklarings)

Q1. Sugar illness/ diabetes is a condition whereby the body:

- ☐ has a higher sugar level in the blood as normal
- ☐ has a lower sugar level in the blood as normal
- ☐ I don't know

Suikersiekte/diabetes is 'n toestand waarby die liggaam:

- ☐ 'n Hoër suikervlak in die bloedstroom het as normal
- ☐ 'n Laer suikervlak in die bloedstroom het as normal
- ☐ Ek weet nie

Q2. The biggest cause of sugar illness /diabetes is:

- ☐ too much insulin in the body
- ☐ too little insulin in the body
- ☐ I don't know

Die grootste oorsaak van suikersiekte/diabetes is:

- ☐ Te veel insulin in die liggaam
- ☐ Te min insulin in die liggaam
- ☐ Ek weet nie

Q3. The signs and symptoms of sugar illness/ diabetes is :

- ☐ Going to the toilet to pass urine more frequently
- ☐ Excessive hunger and thirst
- ☐ Excessive tiredness
- ☐ wounds/ sores takes longer to heal
- ☐ I don't know

Die tekens van suikersiekte/diabetes is:

- ☐ Gaan meer tye toilet toe om te urineer
- ☐ Voel meer honger en dors
- ☐ Voel meer moeg
- ☐ Wonde/sere vat langer om gesond te raak
- ☐ Ek weet nie

Q4. Sugar illness/ diabetes that is not treated :

- ☐ Can cause eye problems
- ☐ Can cause kidney problems
- ☐ Can cause foot sores
- ☐ Can cause heart problems
- ☐ I don't know

Suikersiekte/diabetes wat nie behandel word nie:

- ☐ Kan oog probleme veroorsaak
- ☐ Kan nier probleme veroorsaak
- ☐ Kan voetsere veroorsaak

☐ Kan hart probleme veroorsaak

☐ Ek weet nie

Q5. The best way to monitor your sugar illness/ diabetes is to:

☐ test your blood sugar levels

☐ test the sugar in your urine

☐ HbA1c

☐ I don't know

Die beste manier om suikersiekte/diabetes te monitor is deur die:

☐ Toets van die bloed suiker vlakke

☐ Toets van suiker in die urine

☐ HbA1c

☐ Ek weet nie

Q6. In patients with diabetes high blood pressure can increase the risk of

☐ heart attack

☐ strokes

☐ eye problems

☐ kidney problems

☐ I don't know

Hoë bloeddruk kan vir pasiente met suikersiekte/diabetes die risiko's vererger vir:

☐ Hartaanval ☐ Beroerte ☐ Oog probleme

☐ Nierprobleme ☐ Ek weet nie

Q7. A person that suffers from sugar illness/ diabetes must have his/her blood pressure checked:

☐ Once a year

☐ once every six months

☐ once every two months

☐ once every month

☐ Need not check at all ☐ I don't know

n Pasient wat lei aan suikersiekte/diabetes moet sy/haar bloeddruk laat neem:

☐ Eenkeer per jaar

☐ Eenkeer elke ses maande

☐ Eenkeer elke twee maande

☐ Eenkeer elke maand

☐ Benodig nie om dit te neem nie ☐ Ek weet nie

Q8. in order to live healthy when you are suffering from sugar illness/diabetes, you need to do the following changes in your lifestyle

☐ loose weight ☐ stop smoking ☐ stop using alcohol ☐ healthy diet

☐ Regular physical activity(Exercise) ☐ I don't know

Om gesond te leef wanneer u/jy lei aan suikersiekte/diabetes, benodig u/jy om die volgende veranderinge aan u/jou leefstyl te doen

☐ Verloor gewig ☐ Hou op rook

☐ Hou op met die gebruik van alcohol

☐ Gesonde diët

☐ Gereelde fisiese oefening ☐ Ek weet nie

Q9. a person that suffers from sugar illness/diabetes must have his eyes tested:

☐ Once a year

☐ Once every six months

☐ Need not check at all

n Pasient wat lei aan suikersiekte/diabetes moet sy/haar oë laat toets:

☐ Eenkeer per jaar

☐ Eenkeer elke ses maande

☐ Benodig nie om dit te toets nie

Q10 a balanced diet includes:

☐ green leafy vegetables ☐ high fibre foods ☐ foods low in sugar, oil and fat ☐ all of the above

☐ I don't know

n Gebalanseerde diët sluit in:

☐ Groen blaar groente

☐ Velselryke kosse

☐ Lae suiker, olie en vet

☐ Alles wat genoem is

☐ Ek weet nie

Q11 for proper foot care, a person with sugar illness/ diabetes must

- ☐ wash and inspect the feet daily ☐ choose the most appropriate/ comfortable shoes ☐
☐ walk bare foot in and outside of the house ☐ must not walk barefoot in and outside of the house ☐

Vir 'n behoorlike voetversorging, moet 'n pasient wat lei aan suikersiekte/diabetes:

- ☐ Die voete daaglik was en ondersoek ☐ Kies die mees gepaste/gemaklikste skoene ☐
☐ Loop kaalvoet binne en buite die huis ☐ Moet nie kaalvoet loop binne en buite die huis nie ☐

Q12. The treatment of sugar illness/ diabetes include:

- ☐ treatment with antibiotics ☐ blood transfusion ☐ taking of insulin injections ☐ tablets ☐ I don't know

Die behandeling van suikersiekte/diabetes sluit in:

- ☐ Behandeling met antibiotika ☐ Bloed oortappings ☐ Neem van insulien inspuitings ☐ Pille
☐ Ek weet nie

Q13 sugar illness/ diabetes cannot be treated with:

- ☐ Insulin ☐ metformin ☐ antibiotics ☐ I don't know

Suikersiekte/diabetes kan NIE behandel word met:

- ☐ Insulien ☐ Metformin ☐ Antibiotika ☐ Ek weet nie

Q14. As soon as the diabetes is under control your medication can be

- ☐ stopped immediately ☐ stopped after a month ☐ must be taken for life
☐ I don't know

Sodra die suikersiekte/diabetes onder beheer is kan u/jy die medikasie:

- ☐ Onmiddelik stop ☐ Stop na 'n maand ☐ Moet lewenslank geneem word
☐ Ek weet nie

Q15 do you have any religious or cultural practices or beliefs that would influence how you would care for your diabetes

- ☐ Yes ☐ No

: If yes, please explain

.....
.....
.....
.....
.....

Het u/jy enige godsdienstige of kulturele praktyke of oortuigings wat beïnvloed hoe u/jy na u/jou suikersiekte/diabetes kyk

- ☐ Ja ☐ Nee

Indien ja, verduidelik

.....

Q16.? To help us understand the health needs of the different communities we would like to know in which one of the following race groups you would classify yourself.

☐ black south African ☐ white ☐ coloured ☐ indian(Asian) ☐ Other(specify)

Dit help ons om te verstaan die gesondheids behoeftes van die verskillende gemeenskappe en vir dié rede wil ons graag weet in watter van die volgende groupe u/jy uself/jouself sal klassifiseer

☐ Swart Suid Afrikaans ☐ Wit ☐ Kleurling ☐ Indian (Asian) ☐ Ander (Spesifiseer)

E. (

Item	Date	Visit I	Visit II	Visit III
Fasting blood glucose level/mg/dl				
HbA1c %				
Blood pressure				

Item	Datum	Besoek I	Besoek II	Besoek III
Vastende bloedglukose vlak / mg / dlblem				

HbA1c %				
Bloed druk				

(Hierdie gedeelte moet deur die Personeel (field-workers) voltooi word)

Glukose + BP data vir die laaste drie besoeke (Soos in pasient leer)

F. Social Support Scale

You might think that some of these questions has already been asked, but in this section we ask you questions regarding your family and friends

Q1. My family and friends supports me a lot to: (circle one answer per line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a) Follow my diet/ healthy eating plan	1	2	3	4	5	N/A
b) take my medication	1	2	3	4	5	N/A
c) Care for my feet	1	2	3	4	5	N/A
d) Getting enough exercise/ physical activity	1	2	3	4	5	N/A
e) Testing my blood sugar levels	1	2	3	4	5	N/A
f) Handle my feelings about diabetes	1	2	3	4	5	N/A

F. Sosiale ondersteunings skaal

U/jy mag dink dat sommige van die volgende vrae alreeds gevra was, maar in die deel vra ons oor u/jou familie en vriende

Q1. My familie en vriende help en ondersteun my baie om : (Omkring een antwoord per lyn)

	Stem nie heeltemal saam nie	Stem nie ietwat saam nie	Neutraal	Stem ietwat saam	Stem heeltemal saam	Is nie gepas nie
a) Volg my eetplan	1	2	3	4	5	N/A
b. Neem my medikasie	1	2	3	4	5	N/A
c. Sorg vir my voete	1	2	3	4	5	N/A
d. Kry genoeg fisiese aktiwiteite/oefening.	1	2	3	4	5	N/A
e. Toets my bloedsuiker vlakke .	1	2	3	4	5	N/A
f. Hanteer my gevoelens oor suikersiekte/diabetes	1	2	3	4	5	N/A

Q2. My family and friends(circle one answer per line)

	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree	Does Not Apply
a. Accepts me and my diabetes	1	2	3	4	5	N/A
b. Feels uncomfortable around me due to my diabetes	1	2	3	4	5	N/A
c. Encourages me and reassures me about my diabetes	1	2	3	4	5	N/A
d. Discourages and upsets me because of my diabetes	1	2	3	4	5	N/A
e. Listens to me if I want to talk about my diabetes	1	2	3	4	5	N/A
f. Complains about my diabetes	1	2	3	4	5	N/A

Q2. My familie of vriende : : (Omkring een antwoord per lyn)

	Stem nie heeltemal saam nie	Stem nie ietwat saam nie	Neutraal	Stem ietwat saam	Stem heeltemal saam	Is nie gepas nie
a. Aanvaar my en my suikersiekte/diabetes .	1	2	3	4	5	N/A
b. Voel ongemaklik rondom my as gevolg van my suikersiekte/diabetes	1	2	3	4	5	N/A
c. Moedig my aan en stel my gerus oor my suikersiekte/diabetes	1	2	3	4	5	N/A
d. Ontmoedig en onstel my oor my suikersiekte/diabetes	1	2	3	4	5	N/A
e. Luister na my as ek wil gesels oor my suikersiekte/diabetes	1	2	3	4	5	N/A
f. Kerm/kla oor my suikersiekte/diabetes	1	2	3	4	5	N/A

Title of study: Development of self-management programme for older people with type 2 diabetes attending community health centres in Cape Town metropole.

**Appendix (B) Informed Consent Form
(For the participants in the questionnaire survey)**

Name of Principle investigator:

Professor Dinky Naomi Levitt.

Name of Co-investigator:

Dr Sebastiana Kalula

Name of Student:

Dr Mahmoud Werfalli

Dear Sir/Mam

You are invited to participate in a research project conducted by the Chronic Diseases Initiative in Africa (CDIA) based in the Department of Medicine at the University of Cape Town. We would like to ask you to take part in this study. By taking part in this study, you will help us to understand what people with diabetes attending community health centers know about diabetes and how they take care of themselves.

This information sheet provides some information to help you decide whether to do so. If there is anything that you do not understand, or if you would like more information, please ask us. Please take time to consider whether you wish to take part.

1. Why is this study being done?

I am a PhD student in medicine at the University of Cape Town and this study is part of my degree. The main reason we are doing this study is to know more about diabetes in the older person. We specifically want to better understand how people with diabetes mellitus take care of themselves. This will help us to develop a program to improve the care for the

older person with diabetes in Cape Town. I believe the study is also important in helping health care staff gain a better understanding of how you manage your diabetes.

2. Do I have to take part?

All adults (60 years and over and have diabetes) who attend this community health center clinic are eligible to take part. It is up to you to decide if you want to take part in this study. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to take part, we will ask you to sign a consent form and give you a copy for you to keep. However, you would still be free to withdraw from the study at any time, without needing to give a reason.

3. What will happen to me if I decide to take part?

3.1. Written consent.

If you decide you would like to take part in the study the field work assistant will ask you to sign a consent form. You will be given a copy of this form to keep.

3.2. Study questionnaire

The field work assistants will ask you to complete a questionnaire, which is designed to find out what you know about your diabetes and how you manage it. You may write down your responses or the field worker will write down your responses. This will roughly take 30-35 minutes to complete.

4. What are the risks and discomforts of taking part in this study?

There are no foreseeable risks to you associated with participating in this study.

5. Are there any benefits from taking parts in this study?

There are no direct benefits of you participating in the study. It is hoped that the knowledge gained from the study will help identify areas where older people with diabetes will benefit from improved education and support. Snacks will be provided after the interview as appreciation for your participation in this study.

6. What will happen if I start answering the questionnaire but then decide I don't want to carry on?

If you decide you do not want to carry on with the study. You can withdraw from the study at any time and you do not have to give a reason. If you decide to withdraw it will not affect your care or treatment at the clinic.

7. What will happen to the results of the research?

The research will be published in medical journals. We will inform the Department of Health of the findings.

8. Will I receive any reward for taking part in this study?

No you will not receive any reward.

9. Who will see the information which is collected during the study?

Only the research team of this study will see the information collected during this study. Any information collected about you during this would be kept strictly confidential. Your consent form will be kept in a locked cabinet in a secure building, and will only be accessed by the research team. All other information (your age, gender, date of birth) will be anonymised. A code and not your name will be used so that the results could not be linked back to you. Any personal information about you will be destroyed at the end of the study.

10. What if something goes wrong?

The University has arrangements in place to provide for harm arising from participation in the study for which the university is the Research Sponsor. If you have any concerns about any aspect of this study, please contact one of the study Investigators who will do their best to answer your questions, (**Professor Naomi Levitt**, who can be telephoned at **0214066474.**), (**Dr Sebastiana Kalula**) **0214066211**) and (**Mahmoud Werfalli** **0214066582**) .

If you remain unhappy, and wish to make a complaint, you may contact the University of Cape Town Human Research Ethics Committee office **on 021 406 6492** or the head of Human research Ethics Committee, **Professor Marc Blockman** on **0214066338**

11. Who has reviewed this study?

All research studies are checked by an ethics committee to ensure the research is conducted safely and to the best standards. This research has been reviewed by and received ethics clearance through the University of Cape Town Human Research Ethics Committee.

12. Who is organizing and funding the research?

The research is organized in the Department of Medicine at Groote Schuur Hospital and the University of Cape Town. It is funded by the Department of academic scholarships, Ministry of higher education. Libya

Declaration by the study participant

I have read, or had read to me, this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study. I have received a copy of this agreement.

I understand I may withdraw without question from the study at any time and my withdrawal will not affect my future care.

PARTICIPANT'S NAME: -----

CONTACT DETAILS: -----

PARTICIPANT'S SIGNATURE: -----

Date: -----

Statement of researcher's responsibility

I have explained the nature and purpose of this research study and the procedures to be undertaken. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE: -----

Thank you for taken the time read this information sheet

Table. S1. Mean Diabetes Knowledge, self-management practice and social support scores of the participants by socio-demographic characteristics.

Variables		N	Total knowledge score		Total self-management practice score		Total social support score	
			Mean	(SD)	Mean	(SD)	Mean	(SD)
Sex	Male	126	45.0	12.7	54.2	19.9	79.7	20.7
	Female	280	47.7	13.1	53.6	17.3	75.3	20.8
	* P value		0.053		0.76		0.048	
Age group	60-69	257	47.8	11.9	53.3	18.7	76.7	19.9
	70-79	121	45.6	15.2	54.3	16.9	76.4	22.7
	80 or above	28	42.6	11.3	55.2	18.5	79.3	20.8
	+ P value		0.21		0.10		0.54	
Level of Education								
	None / some primary school	233	45.7	12.4	51.5	18.2	77.7	20.4
	Some high school	150	47.6	13.5	54.9	17.5	75.1	21.0
	Matric / Tertiary	12	50.1	10.1	58.4	17.7	77.8	20.3
	# P value		0.008		0.180		0.817	
Marital status	Single	44	41.2	12.9	54.5	17.4	78.7	22.7
	Married	209	46.7	12.5	54.4	18.5	77.4	20.1
	Divorced/ Separated	65	45.5	15.1	50.1	18.00	74.5	20.3
	Others	88	49.4	12.7	54.2	17.3	75.2	21.8
	+ P value		0.008		0.68		0.83	
Race								
	Coloured (mixed race)	312	47.0	12.7	53.2	18.3	76.5	20.7
	Other (White, Black, Indian and other	94	47.2	13.3	55.9	17.6	77.0	21.7
	* P value		0.21		0.20		0.84	
Who are Living with								
	Spouse	52	49.6	12.1	55.4	18.3	67.7	21.0
	Family member	246	46.8	13.1	54.3	17.8	77.3	20.6
	Friend/ More than one	83	45.7	14.7	55.5	19.5	82.3	18.0
	Alone	25	45.0	12.3	50.6	18.5	75.0	21.5
	+ P value		0.24		0.35		0.001	
Monthly family income								
	Less than R 1 500	350	46.6	12.9	54.1	18.4	77.0	21.0
	R 1 500 or more	46	47.6	14.3	53.1	14.0	74.8	20.1
	* P value		0.63		0.69		0.48	

* t-test for Equality of Means (Sig. (2-tailed), + ONE-WAY ANOVA test,

+

Others: have a joint household, live together. cohabit

Table S2.. Mean Diabetes Knowledge, self-management practice and social support scores by clinical characteristics of the Participants.

Variables		N	Total knowledge score		Total self-management practice score		Total social support score	
			Mean	(SD)	Mean	(SD)	Mean	(SD)
Duration of Diabetes								
	Less than 5 years	125	45.3	14.03	55.	16.8	77.0	19.8
	5-10 years	158	47.3	13.07	52.0	19.5	75.2	22.3
	11-16 years	84	48.2	11.8	53.7	19.0	79.0	18.9
	>17 years	36	46.9	12.1	56.0	13.8	76.3	22.5
	*P value		0.42		0.34		0.59	
Type of medication used								
	Insulin injections	28	43.3	13.9	52.9	17.1	77.9	26.0
	Pills	250	47.6	13.1	52.5	17.9	76.7	20.1
	Both	125	46.1	12.6	56.2	18.7	76.8	21.2
	+ P value		0.19		0.18		0.95	
Have you experienced low blood sugar	No	333	45.9	13.2	53.2	18.4	77.02	21.5
	Yes	73	51.2	11.2	56.7	16.5	75.2	18.0
	* P value		.001		0.12		.45	
Have you experienced high blood sugar	No	211	45.1	13.5	55.0	16.6	78.5	19.8
	Yes	195	48.7	12.2	52.2	19.6	74.7	21.8
	* P value		.005		.092		.064	
Receiving medication for chronic hypertension								
	No	100	45.2	13.0	54.18	17.8	75.8	21.27
	Yes	306	47.4	13.0	53.7	18.3	76.9	20.8
	* P value		0.15		0.83		.63	
Receiving medication for heart disease								
	No	345	46.4	13.0	54.7	17.9	76.6	20.4
	Yes	61	49.4	13.0	48.7	18.8	77.0	23.7
	* P value		.097		.017		0.88	

Receiving medication for other chronic disease(s)	No	268	45.9	13.4	53.7	18.6	76.2	21.0
	Yes	138	48.7	11.9	53.9	17.1	77.7	20.7
	* P value		0.038		0.93		0.48	
Hospitalised in past 12 months	No	20	48.8	13.1	43.6	22.1	70.8	23.0
	Yes	382	46.7	13.0	54.5	17.7	76.3	20.8
	* P value		0.48		.042		0.20	
‡ Blood glucose control achieved	Not achieved (<5.0 or >7.2 mmol/l)	331	46.9	13.3	54.1	18.5	77.	20.0
	Achieved (5.0 -7.2 mmol/l)	71	46.3	11.9	52.2	16.6	72.7	24.1
	P value		0.70		0.43		0.12	

‡ For blood glucose control according to Krikman criteria, 2012, the range (Not achieved (<90 or >130), Achieved (90-130))

Table S3. Association of socio-demographic variables, HbA1c and social support with knowledge score

Variable	β	95% CI	P value
Female	0.660	-0.285; 1.604	0.160
Age group, years (ref = 55-69 years)			
70-79 years	-0.461	-1.495; 0.572	0.380
>80 years	-1.893	-3.754; -0.031	0.046
Education level (ref = None / some primary school)			
Some or completed High school/Tertiary education	0.639	-0.273; 1.550	0.169
Income >R1500 (ref = <R1500)	0.324	-1.013; 1.661	0.634
Living alone (ref = Living with Family/friends/spouse)	0.111	-1.668; 1.889	0.903
HbA1c >8% (ref = HbA1c <8%)	-0.272	-1.183; 0.638	0.557
Social support	-0.018	-0.093; 0.058	0.649

Multivariable linear regression was used to evaluate the associations between knowledge (dependant variable) and sociodemographic variables (gender, age group, education level, income, living environment, glycaemic control and social support (independent variables).

Adjusted R-squared – 1.0%, Prob > F = 0.206

Table S4. Association of socio-demographic variables, HbA1c and social support with self-management practice score

Variable	β	95% CI	P value
Female	1.230	-0.372; 2.831	0.131
Age group, years (ref = 55-69 years)			
70-79 years	0.510	-1.178; 2.199	0.551
>80 years	0.443	-2.505; 3.392	0.767
Education level (ref = None / some primary school)			
Some or completed High school/Tertiary education	-0.038	-1.592; 1.516	0.961
Income >R1500 (ref = <R1500)	3.434	0.797; 6.070	0.011
Living alone (ref = Living with Family/friends/spouse)	-0.725	-3.496; 2.047	0.606
HbA1c >8% (ref = HbA1c <8%)	0.117	-1.427; 1.660	0.881
Social support	-0.061	-0.065; 0.188	0.340

Multivariable linear regression was used to evaluate the associations between self-management practice score (dependant variable) and sociodemographic variables (gender, age group, education level, income, living environment, glycaemic control and social support (independent variables).

Adjusted R-squared – 1.3%, Prob > F = 0.275

Study 4: Supplementary Materials

**This appendix formed part of the original submission and
has been peer reviewed.**

Title	Author and date of publication	Sourced
White Paper for Social Welfare	Ministry of Social Development 1994	www.gov.za/sites/default/files/White_Paper_on_Social_Welfare_0.pdf .
Older Person's Act (Act 13 of 2006)	SA Parliament	www.westerncape.gov.za/legislation/older-persons-act-13-2006 .
SA National Plan of Action on Ageing	Ministry of Social Development 2002	www.tafta.org.za/images/SAPlanofActiononAgeing.pdf .
South Africa's Progress on the Implementation of the Madrid Plan of Action on Ageing	Ministry of Social Development 2007	http://libguides.lib.uct.ac.za/c.php?g=214526&p=1579027 .
Policy implications and challenges of populations ageing in South Africa	Goodrick WF, 2013	scholar.google.com/scholar .
Vulnerable Groups Series II: The Social Profile of Older Persons, 2011–2015	Statistics South Africa 2017	http://www.statssa.gov.za/publications/Report%2003-19-03/Report%2003-19-032015.pdf .
Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) issued the first edition of the Consensus Guidelines for the management of type 2 diabetes	JEMDSA, 2017, Vol 22, no 1, Supp 1, pages S1-S196	www.semDSA.org.za/images/647-4385-1-pb.pdf .
Master's Thesis in Sociology, University of Free State, 2013: Policy implications and challenges of population ageing in South Africa	Wade Francis Goodrick	http://scholar.ufs.ac.za:8080/xmlui/handle/11660/1879 .
The Samson Institute for Ageing Research (SIFAR)		http://www.sifar.org.za .
SA Strategic Plan for the Prevention and Control of NCDs		http://www.hsrc.ac.za/uploads/pageContent/%20proof.pdf .
SA Health Review 20 th edition, 2017	2017	http://www.hst.org.za/publications/South%20Version.pdf .

Supplementary Table 2: Barriers to self-management experienced by older diabetic patients

Side effects of medication	<p>“Many patients experience side effects with Metformin. We get tons of returned meds in the pharmacy bins. Patients want to be seen as ‘good patients’ and just accept medication, even if they don’t intend using them.” (K1)</p>
Loss of function	<p>“With poor vision and motor control it is difficult for them to give themselves injections and examine their own feet.” (K1)</p> <p>“Many patients have cognitive decline that isn’t diagnosed or acknowledged, so they don’t understand clearly or get confused.” K1)</p> <p>“They get forgetful and can’t remember which pills for what are and if they have even taken them.” K1)</p>
Constrained dietary choices	<p>“The elderly have fewer choices because they are often living with their children and have no say in the shopping or cooking. They just eat what there is to avoid feeling like a burden.” (K5)</p> <p>“They think they need to eat special foods labelled “Diabetic” and these are expensive. Fruit and vegetables are also expensive if you don’t have transport to Wholesalers like Fruit&Veg.” (K5)</p> <p>High carb foods are relatively cheap for the satiety they give. For example, if one is hungry a loaf of bread and polony is cheap and filling.” (K5)</p>
Prevalent social norms around food	<p>“Rejecting food that is offered is seen as rude, especially at a social function like a wedding or birthday. People do not usually cater for diabetics: big life events are celebrated with calorie dense, sugary food.” (K5)</p>
Poverty	<p>“Many of my older patients wear cheap shoes that squeeze their toes and give poor support because they cannot afford sports shoes with thick soles and a wide toe box.” (K3)</p> <p>“It is hard to prioritise good diabetic control, when the emphasis is on just living day to day.” (K3)</p>
Lack of education	<p>“Self-management can be a problem for many older patients because they are not well educated.” (K1 4)</p>

Lack of family support	“Often, they have no support from their families.” (K3)
Constrained opportunity for physical activity	“It is not safe for older patients to walk or exercise outside in areas of high crime.” (K2)
Difficulty accessing healthcare	<p>“Many patients have difficulty with transport to the community health centre or to Orthotics in Pinelands, either because it is not available or too expensive.” (K2)</p> <p>“Some of them are not so mobile and cannot get to the healthcare facility, so they need special care to accommodate them.” (KI 5)</p>
Severely limited consultation time	<p>“Older patients need longer consultations but when you are seeing 35 patients a day, there is no time.” (KI 3)</p> <p>“It is very hard to explain a complex condition with complex therapy in the time allotted and doctors often don’t communicate well.” (KI 3)</p>
Poor communication with healthcare providers	<p>“Generally, communication between providers and patients is very poor. Staff are sometimes impatient and disrespectful, because they are burnt out.” (K2)</p> <p>“Providers tend to use medical terms which patients are not acquainted with. Patients would prefer simple explanations.”</p> <p>“The staff should come down to the patient’s level so that they can feel they are part of the discussion about their health.” (KI 5)</p> <p>“Doctors tend to speak to the family members instead of directly to the older patient. So, the patient is disempowered.” (K3)</p>
Lack of status	<p>“Patients with chronic disease are undervalued by the health system.” (K2)</p> <p>“Most of the people managing diabetics have more interest in the younger people. They say they are the future generation. But that leaves old people with a feeling of being ignored.” (KI 5)</p> <p>“I am interested in managing diabetes in older people as I think they have real problems in managing themselves. Proper education should be provided to them to avoid them feeling rejected due to old age.” (KI 5)</p>
Depression	“Patients are often depressed, and this affects their motivation to live healthily.” (K3)

Multi-morbidity	<p>“It is particularly difficult for the older patient with multi-morbidity: there are too many pills with side effects and drug interactions.” (K3)</p> <p>“Older patients are likely to be taking more than one chronic medication, which means they need closer monitoring as there may be drug interactions.” (KI 5)</p> <p>“Each co-morbidity affects the other. For example, a patient with Osteo arthritis or Chronic Obstructive Pulmonary Disease finds it difficult to exercise.” (K3)</p> <p>“Food that might be good for one condition, may not be good for another. For example, diabetic patients should eat more greens, but a patient on warfarin should avoid spinach because it has vitamin K, which thickens the blood.” (KI 5)</p> <p>“Once you have checked on all the different conditions, there is little time to focus on diabetes. Patients with co-morbidities especially need longer consultation times.” (KI1)</p>
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Study 5: Supplementary Materials

This appendix formed part of the original submission

Additional File 1. Search Strategy

A. Search strategy structure (A AND B AND C OR D AND E)

(A) "diabetes mellitus"[MeSH Terms] OR ("diabetes"[All Fields] AND "mellitus"[All Fields]) OR "diabetes mellitus"[All Fields] OR "diabetes"[All Fields] OR "diabetes insipidus"[MeSH Terms] OR ("diabetes"[All Fields] AND "insipidus"[All Fields]) OR "diabetes insipidus"[All Fields]) AND (Clinical Trial[ptyp] AND "aged"[MeSH Terms])) AND (peer support diabetes AND Clinical Trial[ptyp])

(B) AND (((((((((((((((peer[All Fields] AND based[All Fields] AND interventions[All Fields]) OR (peer-led[All Fields] AND interventions[All Fields])) OR (peer[All Fields] AND ("education"[Subheading] OR "education"[All Fields] OR "educational status"[MeSH Terms] OR ("educational"[All Fields] AND "status"[All Fields]) OR "educational status"[All Fields] OR "education"[All Fields] OR "education"[MeSH Terms])))) OR "Social Support"[Mesh]) OR peers[All Fields]) OR (peer[All Fields] AND support[All Fields])) OR (peer[All Fields] AND ("counselling"[All Fields] OR "counseling"[MeSH Terms] OR "counseling"[All Fields])) OR "Self-Help Groups"[Mesh]) OR (("population groups"[MeSH Terms] OR ("population"[All Fields] AND "groups"[All Fields]) OR "population groups"[All Fields] OR "group"[All Fields]) AND support[All Fields])) OR (("population groups"[MeSH Terms] OR ("population"[All Fields] AND "groups"[All Fields]) OR "population groups"[All Fields] OR "group"[All Fields]) AND ("education"[Subheading] OR "education"[All Fields] OR "educational status"[MeSH Terms] OR ("educational"[All Fields] AND "status"[All Fields]) OR "educational status"[All Fields] OR "education"[All Fields] OR "education"[MeSH Terms])) OR (peer[All Fields] AND leader[All Fields])) OR (lay[All Fields] AND ("health educators"[MeSH Terms] OR ("health"[All Fields] AND "educators"[All Fields]) OR "health educators"[All Fields])) OR (lay[All Fields] AND ("manpower"[Subheading] OR "manpower"[All Fields] OR "workers"[All Fields])) OR (lay[All Fields] AND ("health"[MeSH Terms] OR "health"[All Fields]) AND advisor[All Fields])) OR "Community Health Workers"[Mesh]) OR ("community health workers"[MeSH Terms] OR ("community"[All Fields] AND "health"[All Fields] AND "workers"[All Fields]) OR "community health workers"[All Fields] OR ("community"[All Fields] AND "health"[All Fields] AND "worker"[All Fields]) OR "community health worker"[All Fields])) AND

(C) **AND** (Africa or "Latin America" or Caribbean or "West Indies" or "Eastern Europe" or Soviet or "South America" or "Middle East" or "Latin America" or "Central America") or (Afghanistan or Albania or Algeria or Angola or Antigua or Barbuda or Argentina or Armenia or Armenian or Aruba or Azerbaijan or Bahrain or Bangladesh or Barbados or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brasil or Brazil or Bulgaria or Burkina Faso or Burkina Fasso or Upper Volta or Burundi or Urundi or Cambodia or Khmer Republic or Kampuchea or Cameroon or Cameroons or Cameron or Camerons or Cape Verde or Central African Republic or Chad or Chile or China or Colombia or Comoros or Comoro Islands or Comores or Mayotte or Congo or Zaire or Costa Rica or Cote d'Ivoire or Ivory Coast or Croatia or Cuba or Cyprus or Czechoslovakia or Czech Republic or Slovakia or Slovak Republic or Djibouti or French Somaliland or Dominica or Dominican Republic or East Timor or East Timur or Timor Leste or Ecuador or Egypt or United Arab Republic or El Salvador or Eritrea or Estonia or Ethiopia or Fiji or Gabon or Gabonese Republic or Gambia or Gaza or Georgia Republic or Georgian Republic or Ghana or Gold Coast or Greece or Grenada or Guatemala or Guinea or Guam or Guiana or Guyana or Haiti or Honduras or Hungary or India or Maldives or Indonesia or Iran or Iraq or Isle of Man or Jamaica or Jordan or Kazakhstan or Kazakh or Kenya or Kiribati or Korea or Kosovo or Kyrgyzstan or Kirghizia or Kyrgyz Republic or Kirghiz or Kirgizstan or Lao PDR or Laos or Latvia or Lebanon or Lesotho or Basutoland or Liberia or Libya or Lithuania or Macedonia or Madagascar or Malagasy Republic or Malaysia or Malaya or Malay or Sabah or Sarawak or Malawi or Nyasaland or Mali or Malta or Marshall Islands or Mauritania or Mauritius or Agalega Islands or Mexico or Micronesia or Middle East or Moldova or Moldovia or Moldovian or Mongolia or Montenegro or Morocco or Ifni or Mozambique or Myanmar or Myanma or Burma or Namibia or Nepal or Netherlands Antilles or New Caledonia or Nicaragua or Niger or Nigeria or Northern Mariana Islands or Oman or Muscat or Pakistan or Palau or Palestine or Panama or Paraguay or Peru or Philippines or Philipines or Phillipines or Phillippines or Poland or Portugal or Puerto Rico or Romania or Rumania or Roumania or Russia or Russian or Rwanda or Ruanda or Saint Kitts or St Kitts or Nevis or Saint Lucia or St Lucia or Saint Vincent or St Vincent or Grenadines or Samoa or Samoan Islands or Navigator Island or Navigator Islands or Sao Tome or Saudi Arabia or Senegal or Serbia or Montenegro or Seychelles or Sierra Leone or Slovenia or Sri Lanka or Ceylon or Solomon Islands or Somalia or South Africa or Sudan or Suriname or Surinam or Swaziland or Syria or Tajikistan or Tadzhikistan or Tadjikistan or Tadjhik or Tanzania or Thailand or Togo or Togolese Republic or Tonga or Trinidad or Tobago or Tunisia or Turkey or Turkmenistan or Turkmen or Uganda or Ukraine or Uruguay or USSR or Soviet Union or Union of Soviet Socialist Republics or Uzbekistan or Uzbek or Vanuatu or New Hebrides or Venezuela or Vietnam or Viet Nam or West Bank or Yemen or Yugoslavia or Zambia or Zimbabwe or Rhodesia).

(D)OR (((("poverty"[MeSH Terms] OR "poverty"[All Fields] OR ("low"[All Fields] AND "income"[All Fields]) OR "low income"[All Fields]) AND countries[All Fields]) OR (middle[All Fields] AND ("income"[MeSH Terms] OR "income"[All Fields]) AND countries[All Fields])) OR (low-middle[All Fields] AND ("income"[MeSH Terms] OR "income"[All Fields]) AND countries[All Fields]))))

(E) AND (((((interventions [All Fields] OR "Randomized Controlled Trial"[Publication Type]) OR RCT[All Fields]) OR "Controlled Clinical Trial"[Publication Type]) OR CCT[All Fields]) OR experiment[All Fields]) **AND** **(("2000/01/01"[PDAT] : "2017/12/31"[PDAT]) AND "adult"[MeSH Terms])**

Additional file 2

Cochrane Risk of Bias Tool

Domain	Description	High Risk of Bias	Low Risk of Bias	Unclear Risk of bias	Reviewers assessment	Reviewers comments
<i>Selection bias</i> Random sequence generation	Described the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups	Selection bias (biased allocation to interventions) due to inadequate generation of a randomized sequence	Random sequence generation method should produce comparable groups	Not described in sufficient detail	High Low Unclear	
Selection bias Allocation concealment	Described the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen before or during enrollment	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations prior to assignment	Intervention allocations likely could not have been foreseen in before or during enrollment	Not described in sufficient detail	High Low Unclear	
Reporting bias Selective reporting	Stated how the possibility of selective outcome reporting was examined by the authors and what was found	Reporting bias due to selective outcome reporting	Selective outcome reporting bias not detected	Insufficient information to permit judgment†	High Low Unclear	
Performance bias Blinding (participants and personnel)	Described all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provided any information relating to whether the intended blinding was effective.	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.	Blinding was likely effective.	Not described in sufficient detail	High Low Unclear	
Detection bias Blinding (outcome assessment)	Described all measures used, if any, to blind outcome assessors from knowledge of which intervention a participant received.	Detection bias due to knowledge of the allocated interventions by outcome assessors.	Blinding was likely effective.	Not described in sufficient detail	High Low Unclear	

	Provided any information relating to whether the intended blinding was effective					
Attrition bias Incomplete outcome data	Described the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. Stated whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported.	Attrition bias due to amount, nature or handling of incomplete outcome data.	Handling of incomplete outcome data was complete and unlikely to have	Insufficient reporting of attrition/exclusions to permit judgment (e.g., number randomized not stated, no reasons for missing data provided)	High Low Unclear	

Additional file 3

Risk of bias of included studies

Author: (Zhong 2015)			Study design: RCT			Country: China		
ITEM			AUTHORS' JUDGMENT			SUPPORT FOR JUDGMENT		
Selection bias Random sequence generation			Unclear risk			Insufficient information.		
<i>Selection bias</i> <i>Allocation concealment</i>			Unclear risk			Insufficient information.		
<i>Detection bias</i> <i>Blinding (outcome assessment</i>			High Risk			Community nurses collecting outcome data could not be blinded to allocation due to nature of intervention/control		
<i>Attrition bias</i> <i>Incomplete outcome data</i>			High risk			Acknowledge loss to follow up. However, ITT analysis wasn't attempted.		
<i>Reporting bias</i> <i>Selective reporting</i>			Low risk			The main primary and secondary outcomes were stated.		
<i>Performance bias</i> <i>Blinding (participants and personnel)</i>			Unclear risk			Authors acknowledge that patients receiving the intervention were seen at the same clinic as the control group. It is thus possible that the presence of peer leaders influenced the usual care group.		
Author: (Gargliardino 2014)			Study design: RCT			Country: Argentina		
ITEM			AUTHORS' JUDGMENT			SUPPORT FOR JUDGMENT		
Selection bias Random sequence generation			Unclear risk			Insufficient information.		
<i>Selection bias</i> <i>Allocation concealment</i>			Unclear risk			Insufficient information.		
<i>Detection bias</i> <i>Blinding (outcome assessment</i>			High Risk			It was not possible to blind outcome assessors due to nature of intervention/control.		
<i>Attrition bias</i> <i>Incomplete outcome data</i>			Unclear risk			Insufficient information.		
<i>Reporting bias</i> <i>Selective reporting</i>			Low risk			The main outcomes were stated.		
<i>Performance bias</i> <i>Blinding (participants and personnel)</i>			High risk			It was not possible to blind the peer , patients o due to nature of intervention/control		
Author: (Mash 2014)			Study design: RCT			Country: South Africa		
ITEM			AUTHORS' JUDGMENT			SUPPORT FOR JUDGMENT		
Selection bias Random sequence generation			Low risk			Computer-generated random numbers were used		
<i>Selection bias</i> <i>Allocation concealment</i>			Unclear risk			Insufficient information.		
<i>Detection bias</i> <i>Blinding (outcome assessment</i>			High Risk			It was not possible to blind the data collection teams as to whether the health centre was a control or intervention site.		

<i>Attrition bias</i> <i>Incomplete outcome data</i>	Low risk	Missing data were imputed using appropriate methods, including logistic regression and inverse probability weighting.
<i>Reporting bias</i> <i>Selective reporting</i>	Low risk	The study was conducted according to a protocol containing pre-specified outcomes
<i>Performance bias</i> <i>Blinding</i> <i>(participants and personnel)</i>	High	It was not possible to blind the peers, patients to whether the health centre was a control or intervention site
Author: (Liu et al. 2012) Study design: RCT Country: China		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	Low risk	Participants in the same community were randomized into "intervention group" and "control group", according to a random-number table with a randomization ratio designed to yield no fewer than 20 and no more than 25 participants in a group."
<i>Selection bias</i> <i>Allocation concealment</i>	Low risk	Investigators and assessors (those collecting and analysing data) were blinded to group assignments.
<i>Detection bias</i> <i>Blinding (outcome assessment)</i>	Low risk	Data collection was completed by university students who did not know the patients or their intervention status.
<i>Attrition bias</i> <i>Incomplete outcome data</i>	High	The study report fails to include results for a key outcome that would be expected to have been reported for such a study. No data on HbA1c levels nearly 15% of participants did not complete the study, which may cause bias results."
<i>Reporting bias</i> <i>Selective reporting</i>	Low risk	The study protocol is available and all of the study's pre-specified (primary and secondary) outcomes that are of interest in the review have been reported in the pre-specified way
<i>Performance bias</i> <i>Blinding</i> <i>(participants and personnel)</i>	High risk	Participants were aware of their treatment assignments." The blind wasn't effective
Author: (Wu et al. 2011) Study design: RCT Country: Taiwan		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	Low risk	Participants were randomly assigned to either the control group or the intervention group by using a random number table.
<i>Selection bias</i> <i>Allocation concealment</i>	Unclear risk	Insufficient information.
<i>Detection bias</i> <i>Blinding (outcome assessment)</i>	High Risk	It was not possible to blind outcome assessors due to nature of intervention/control.
<i>Attrition bias</i> <i>Incomplete outcome data</i>	Low risk	The characteristics of those who dropped out were similar to those who participated in the study "Other significant outcomes (HbA1c, Body Mass Index, blood pressure, and body weight) were not measured in this study.
<i>Reporting bias</i> <i>Selective reporting</i>	High Risk	other significant outcomes (HbA1c, Body Mass Index, blood pressure, and body weight) were not measured in this study.

<i>Performance bias Blinding (participants and personnel)</i>	High Risk	<ol style="list-style-type: none"> 1. It was not possible to blind the peer , patients due to nature of intervention/control. 2. The effects of the SEEIP in this study might have been influenced by a Hawthorne effect due to the increased amount of attention that was paid to the participants in the intervention group by the group facilitator.
Author: (Assah et al., 2015)	Study design: Non-randomized Control Trial	Country: Cameroon
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	non-randomized controlled trial 200 adults with poorly controlled Type 2 diabetes (HbA1c > 7%) were initially recruited from the National Obesity Centre, at the Yaoundé Central Hospital. One hundred subjects were recruited into the intervention arm; Thereafter, 96 age and sex-matched controls were recruited into the control arm.
<i>Selection bias Allocation concealment</i>	High risk	No
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind outcome assessors due to nature of intervention/control
<i>Attrition bias Incomplete outcome data</i>	Unclear risk	Insufficient information.
<i>Reporting bias Selective reporting</i>	High risk	One or more outcomes of interest in the review are reported incompletely so that they cannot be entered in a meta-analysis. In the control group, the only data collected was HbA1c; in the intervention group BP, cholesterol, BMI, etc. Was also obtained.
<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer, patients o due to nature of intervention/control
Author : (Micikas M .2014)	Study design: a pre-post quasi experimental	Country: Guatemala
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	no information.
<i>Selection bias Allocation concealment</i>	High risk	no information.
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind the data collection teams due to nature of intervention/control
<i>Attrition bias Incomplete outcome data</i>	Unclear risk	Insufficient information. Provided.
<i>Reporting bias Selective reporting</i>	High risk	The survey instrument used in the study was designed for Latino populations in Atlanta and includes measures that seek to quantify levels of physical activity, food intake, depression, and social support scales which did not translate well to the cultural context of this community

<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer , patients due to nature of intervention/control.
(Baumann 2014) Study design: a pre-post quasi experimental Country: Uganda		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	The method didn't specify
<i>Selection bias Allocation concealment</i>	High risk	The method didn't specify
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind outcome assessors due to nature of intervention/control
<i>Attrition bias Incomplete outcome data</i>	Low risk	information on reasons for missing data provided
<i>Reporting bias Selective reporting</i>	Low risk	All stated outcome measures reported
<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer , patients due to nature of intervention/control.
(Huixia Shen 2008) Study design: pre-post quasi experimental Country: China (Thesis)		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	No
<i>Selection bias Allocation concealment</i>	High risk	A quasi-experimental, nonequivalent control group design was used and. Subjects are not randomly assigned.'
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind outcome assessors due to nature of intervention/control.
<i>Attrition bias Incomplete outcome data</i>	Unclear risk	Insufficient information.
<i>Reporting bias Selective reporting</i>	Low risk	The study protocol is available and all about outcomes that are of interest have been reported in the pre-specified way.
<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer , patients due to nature of intervention/control
(Eggermont N 2011) Study design: before-after study design Country: Cambodia (thesis)		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	No
<i>Selection bias Allocation concealment</i>	High risk	No
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind outcome due to nature of intervention/control.
<i>Attrition bias Incomplete outcome data</i>	Unclear risk	Insufficient information.
<i>Reporting bias Selective reporting</i>	Low risk	All stated outcome measures reported

<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind peer and patients due to nature of intervention/control.
(Rotheram-Borus et al 2012) Study design: before-after study Country: South Africa		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	No
<i>Selection bias Allocation concealment</i>	High risk	No
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind the outcome assessors due to nature of intervention/control
<i>Attrition bias Incomplete outcome data</i>	Low risk	reasons for missing data provided.
<i>Reporting bias Selective reporting</i>	Low risk	The main outcomes were stated.
<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer and patients due to nature of intervention/control
(Less 2010) Study design: Before and after study Country: Jamaica		
ITEM	AUTHORS' JUDGMENT	SUPPORT FOR JUDGMENT
Selection bias Random sequence generation	High risk	No
<i>Selection bias Allocation concealment</i>	High risk	No
<i>Detection bias Blinding (outcome assessment)</i>	High risk	It was not possible to blind the outcome assessors due to nature of intervention/control.
<i>Attrition bias Incomplete outcome data</i>	Low risk	reasons for missing data provided.
<i>Reporting bias Selective reporting</i>	Low risk	The main outcomes were stated.
<i>Performance bias Blinding (participants and personnel)</i>	High risk	It was not possible to blind the peer and patients due to nature of intervention/control.